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ABSTRACT

Presented are 37 position papers and two addresses given at the national conference of the National Advisory Council on Services and Facilities for the Developmentally Disabled in November, 1972. Cited are conference objectives to encourage understanding and effective implementation of the Developmental Disabilities Act of 1970, provide technical assistance in planning and evaluating services for the disabled, strengthen communications among state and national council members and staff, and provide a forum for issues related to extention and modification of the Act. The principal addresses urge action on behalf of individuals disabled developmentally in childhood, and explain fiscal synergism in the Office of Management and Budget to advance the nation's social goals, respectively. Seven papers focus on planning and evaluation of programs at the community and state levels, while three papers center on reaching special populations among the developmentally disabled. Use of federal resources through programs such as the vocational rehabilitation state plan, maternal child health plan, and the Social Security Act is discussed in nine papers. Two papers give information on state legislative and administrative action. Delineated in five papers are special services related to such factors as residential arrangements and transportation. Future national strategy is the subject of three papers, and delivery of services is examined in four papers. State advisory programs and sources of funds for innovative programs are both covered with two papers. (MC)

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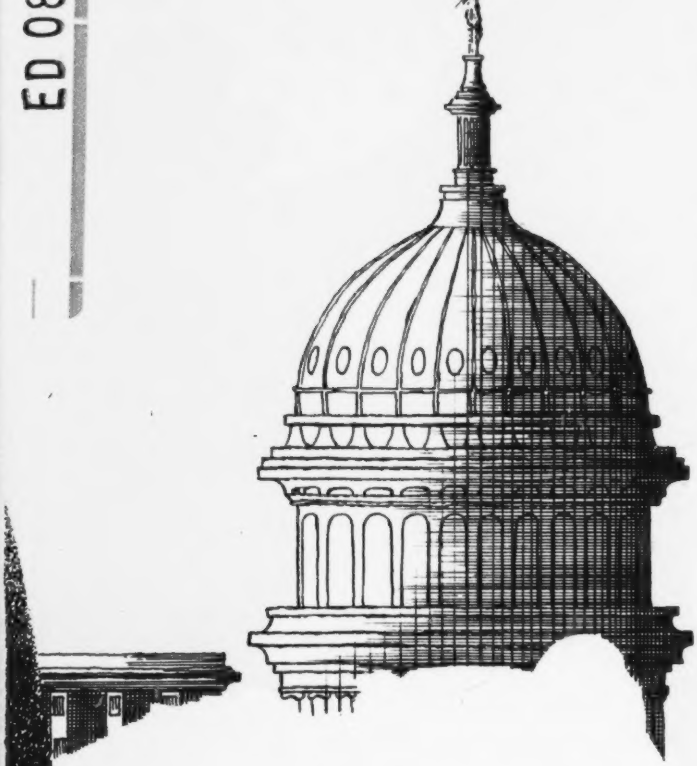
Synergism for the Seventies



Conference Proceedings of the National Conference for State Planning and Advisory Councils on Services and Facilities for the Developmentally Disabled.

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TABLE OF CONTENTS

Page

Preface ... i
Contributors ... iii

PART I: Principal Addresses

1. Disability Originating in Childhood: Challenge to Action
Richard E. Mastrangelo ... 3
2. Fiscal Synergism: The Role of OMB in Advancing the Nation's Social Goals
Paul H. O'Neill ... 9

PART II: Planning and Evaluation

3. The Planning Process for the Developmentally Disabled
Frank Laski ... 21
4. Priority Setting in the Planning Process
Anthony J. Arangio ... 31
5. Planning at the Community Level
Leopold Lippman ... 55
6. Planning Environments Responsive to New Program Concepts
Michael J. Bednar ... 65
7. Essentials of Program Evaluation
Donald J. Stedman and Richard C. Surles ... 81
8. Evaluation of the Impact of State Developmental Disabilities Programs
Seldon P. Todd ... 89
9. Individual Data, Program Evaluation and Longitudinal Research
Richard K. Eyman, George Tarjan and C. Victor Keeran ... 103

PART III: Reaching Special Populations Among the Developmentally Disabled

10. Services for the Developmentally Disabled Within the Inner City
Kelly E. Miller ... 145
11. Reaching the Developmentally Disabled Among Special Disadvantaged Groups
Armando Sanchez ... 161
12. Special Problems and Special Aids in Resolving Special Needs in Rural Areas
James MacDonald Watson ... 169

PART IV: Using Other Federal Resources

13. Services Available to the Developmentally Disabled Through the Vocational Rehabilitation State Plan
Emily M. Lamborn ... 181
14. Services Available to the Developmentally Disabled Through the State Maternal and Child Health Plan
Rudolf P. Hormuth ... 189
15. Services Available to the Developmentally Disabled Through Title XIX of the Social Security Act
Richard L. Humphrey ... 201

16. Services Available to the Developmentally Disabled Through the Mental Health Component of Comprehensive Health Planning
Nathan Sloate 217
17. Services Available to the Developmentally Disabled Through Titles IV and XVI of the Social Security Act
Jerry Turem 221
18. Services Available to the Developmentally Disabled Through Section 314(d) of the Partnership for Health Act
Ellen Z. Fifer 245
19. Use of Vocational Education Programs in Planning for the Developmentally Disabled
Frederick J. Weintraub 255
20. Opportunities Through HUD Funding of Residential Facilities
Mercer Jackson 267
21. Services Available to the Developmentally Disabled Through the Bureau of Education for the Handicapped
Thomas B. Irvin 279

PART V: State Legislative and Administrative Action

22. Dynamics of Change in State Government–Impact Upon the Developmentally Disabled
Allen C. Jensen 299
23. State Legislation and Procedures as They Affect the Developmentally Disabled
Ernest Dean 317

PART VI: Special Services

24. Long Term Care Services for the Developmentally Disabled
Elsie D. Helsel 343
25. Factors in Planning Residential Arrangements for the Developmentally Disabled
Earl C. Butterfield 361
26. The Role of University Affiliated Facilities in the Developmental Disabilities Act
Julius S. Cohen 371
27. Maximum Utilization of Transportation System
William J. Bean 383
28. Case Management, Personal Advocacy and Protective Services
Keith A. Yelinek 393

PART VII: Future National Strategy

29. The Allied Services Bill and Its Implications for Developmental Disabilities
Daniel M. Sprague 409
30. Objectives of "Projects of National Significance"
George N. Bouthilet 419
31. Development and Recognition of Human Rights for the Developmentally Disabled
Stanley Herr 437

PART VIII: Delivery of Services

32. Models of Service Delivery
Edgar W. Pye 449
33. ACF/MR – JCAH Standards: Instrument for Development of Quality Services
Kenneth G. Crosby 457
34. New Skills Required as a Result of New Problems in Administration and Service
Harold L. McPheeters 469
35. Developing Cooperative Efforts Among Public and Private Agencies
Rolf Williams 477

PART IX: State Advisory Councils

36. Organization of State Advisory Councils
George H. Bown 487
37. Project Grant Review at the State Level
Gilbert L. Woodside 497

PART X: Innovative Programs and Sources of Funds

38. New and Successful Programs and Projects
William Allen Ziegler, Jr. 509
39. Little Used Funding Options
Tadashi Mayeda 519

PREFACE

The enactment of new, groundbreaking national legislation, like the birth of a new child, always engenders the establishment of a whole series of new relationships and modes of operation. Such changes inevitably create confusion, doubts and misunderstanding among the thousands of professional and consumer group representatives involved directly or indirectly in the program.

The National Advisory Council on Services and Facilities for the Developmentally Disabled wisely recognized this fact and determined at one of its early meetings that there was a pressing need for a national conference to describe the purposes and philosophies underlying the newly enacted Developmental Disabilities legislation. After careful advanced planning, such a conference was held in Washington, D.C. on November 16-18, 1972.

The specific objectives of the conference were as follows:

- to encourage a better understanding and effective implementation of the Developmental Disabilities Act of 1970 by those charged with its execution;
- to provide technical assistance in planning and evaluating services for the developmentally disabled;
- to develop and extend communications among the National Advisory Council on Services and Facilities for the Developmentally Disabled, the Federal staff and respective state planning and advisory council members and staff;
- to provide a forum for considering the issues related to extension and modification of the Act.

The Conference featured prominent general session speakers who synthesized broad trends and explored new directions in the provision of services to the developmentally disabled. In addition, an open forum involving key legislators and representatives of special interest groups and governmental agencies was held to exchange ideas and positions regarding the Act. However, the real work of the conference took place in the nearly 100 simultaneous workshops which were scheduled over the 3-day period. In all, over 250 professional and citizen leaders participated in these workshops as speakers, moderators, discussants and topic writers.

To stimulate and direct discussions at the various workshops, the Conference planners commissioned 37 topic writers to prepare position papers. These topic writers were instructed to explore relevant facts, issues and implications within the scope of their assigned topic. Their papers were to serve as springboards for workshop discussions.

Each of the topic writers was selected on the basis of his knowledge of the topic at hand. Many were well known figures in the developmental disabilities movement. Others, however, claimed no special expertise in the field but possessed insights from related areas of endeavor which had a distinct bearing on the development and delivery of services to DD clients.

Subsequent to the conference, each of the topic writers was asked to review his paper in light of the discussions which took place at the workshops and make any revisions or addendums which he felt were indicated. Tape recorded proceedings of each workshop were furnished to the relevant topic writer. Although a few general guidelines were offered and specific suggestions on points in need of clarification were forwarded to topic writers, decisions on how to organize and present material growing out of the workshops were left to the discretion of the individual topic writer. As a result there is a small degree of overlap in the factual matters covered in some papers.

The pages which follow contain the revised and edited papers presented at the November conference by the 37 topic writers plus the texts of addresses given by the two general session speakers. A transcript of an open forum discussion on the development and implementation of the Act has been distributed separately by the Division of Developmental Disabilities, RSA, SRS, and HEW. In addition, because it has been published separately, a document on federal/state plan review, which was prepared by the staff of the Massachusetts Bureau of Developmental Disabilities, is not reproduced here.*

While each position paper is largely the product of the individual thoughts of the particular topic writer, an effort has been made to place each paper in an appropriate context by organizing the proceedings into 10 distinct sections, each of which is proceeded by brief introductory notes prepared by the content editor. These notes attempt to set the stage for the reader and provide a brief synopsis of the ground covered by each topic writer.

With these few brief words of explanation as a backdrop, the reader may now turn to the proceedings of the conference. We think you will find many valuable thoughts and provocative insights into the process of planning and delivering services for developmentally disabled individuals. We also trust that you will find the document helpful as you proceed with your personal efforts to open up new vistas of opportunity for handicapped and disabled citizens.

Robert M. Gettings
Content Editor

***_A Guide to Federal/State Plan Review Under the Provisions of the Developmental Disabilities Services and Construction Act_, Council for Exceptional Children, 1972. Copies may be obtained by writing the Developmental Disabilities Technical Assistance System, 625 West Cameron Avenue, Chapel Hill, North Carolina 27514**

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Part I
Principal Addresses

Editor's Notes

The overall tone for the National Conference was set by Richard E. Mastrangelo, Special Assistant to the Secretary of Health, Education and Welfare, in his keynote remarks at the opening general session. He summarized for the participants the views of HEW Secretary Richardson concerning the future role and responsibilities of the Department. Among the symptoms of the maladies facing HEW, he said, are "exaggerated promises, ill-conceived programs, over-advertised 'cures' for intractable ailments, cynical exploitation of valid grievances, entrenched resistance to necessary change, the cold rigidity of centralized authority and inefficient use of scarce resources . . ."

Mastrangelo traced the history leading up to the formulation of the Developmental Disabilities Services and Facilities Construction Amendments of 1970 and cited the enactment of P.L. 91-517 as "a progressive step in programming because it reaches out to embrace disabled individuals with similar needs regardless of traditional categorical labels." He went on to review the major provision of the Act concluding that these provisions are "in keeping with the social consciousness of the day and our efforts at programming toward human betterment."

Quoting Secretary Richardson, Mastrangelo ended by challenging the participants to join in the enormous task of melding the resources of federal, state and local government, as well as the private sector, into a unified force for change on behalf of developmentally disabled children and adults.

Paul H. O'Neill, Assistant Director of the Office of Management and Budget, offered the conferees an illuminating guided tour through the labyinth of the federal budgetary process. He indicated that the Office of Management and Budget, since the inception of its predecessor agency the Bureau of the Budget in 1921, has had three major functions: (1) bringing agency budget estimates into harmony with each other; (2) eliminating duplication in organization and activities; and (3) assuring that agency spending estimates conform to revenue estimates.

O'Neill reviewed for the group the intricacies of the federal budget cycle and also pointed out some of OMB's less publicized activities in the area on management review and analysis. In addition, he explained how OMB approaches the tasks of determining the appropriateness of federal involvement in a particular activity and how societal goals can be achieved in an efficient and balanced manner.

O'Neill concluded his remarks by noting the tremendous growth which has taken place in federal human service programs over the past few years and the great challenge which the enactment of general revenue sharing legislation presents to those interested in the welfare of the developmentally disabled.

Disability Originating in Childhood: Challenge to Joint Action

R. E. Mastrangelo

I'm delighted to be here and to welcome you to Washington in behalf of Secretary Richardson who has asked me to tell you how sorry he is that he cannot be here with you.

Incidentally, as part of your conference materials you have been given a copy of the Secretary's speech to departmental employees called "Responsibility and Responsiveness." I urge each of you to read Mr. Richardson's remarks which are a call by the Secretary to joint action–responsible action on the part of each of his department's more than 100,000 employees.

He categorized that speech as "an overview of departmental undertakings designed to make HEW a more responsible and responsive instrument for serving *all* the *American people!*" The questions Mr. Richardson raises here and the conclusions he draws are pertinent for you who are involved with the developmentally disabled, as well as others who work daily to help individuals with particular problems seek ways to overcome this disability and dependency.

The secretary addressed the reasons for frustrations experienced by those seeking to solve problems like those which concern you not only in that speech, but also in the Landon lecture delivered at Kansas State University. In his

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Richard E. Mastrangelo was appointed in 1969 to his present position as special assistant to the Honorable Elliott L. Richardson, Secretary of Health, Education, and Welfare. He was graduated from Boston University with a B.S. in Public Relations. He did graduate work in the School of Law and was awarded the Juris Doctor degree in 1962 – followed by admission to the Massachusetts Bar. Prior to his present position, Mr. Mastrangelo engaged in private law practice; served as Special Assistant to the Lieutenant Governor, as Assistant Attorney General of Massachusetts, and as Executive Assistant to the Sargent Committee. His professional affiliations and honorary memberships are numerous. In 1970, he won the distinction of being named one of the Outstanding Young Men in America. He is listed in Who's Who in American Politics.

Landon lecture, the Secretary said: "Our national discontent, in the face of such positive measures of our progress, was in effect predicted for us many years ago by Alexis de Tocqueville, when he wrote:

> 'The evil which was suffered patiently as inevitable seems unendurable as soon as the idea of escaping from it crosses men's minds. All the abuses then removed call attention to those that remain, and they now appear more galling. The evil, it is true, has become less, but sensibility to it has become more acute.'

de Tocqueville expressed an insight that has been true for all societies in every age. In our society, however, a revolution of rising expectations has been gathering ever-increasing momentum. Instead of finding satisfaction in the achievement of long sought goals, we wonder why even grander goals elude our grasp. In such a framework, our successes–compared with our ever-escalating expectations–appear as failures.

There is, besides, much actual failure. Exaggerated promises, ill-conceived programs, over-advertised "cures" for intractable ailments, cynical exploitation of valid grievances, entrenched resistance to necessary change, the cold rigidity of centralized authority, inefficient use of scarce resources–all these add to frustration and foster disillusionment."

The Secretary went on to say: "One major cause of the growing gap between promise and performance is the difference between the amount the Congress authorizes in the way of expenditures, and the amount it actually appropriates to do the job.

"For the Department of Health, Education, and Welfare alone, this gap has reached enormous proportions. In 1964, the difference between authorizations and appropriations for HEW programs was $200 million. In the current year, authorizations for HEW exceed appropriations by $6 *billion*. Pending legislation is likely to add another $9 billion to our spending authority–and this at a time when our budget deficit will total $38 billion in the current year.

"Authorizations to spend are rightfully viewed by the public as promissory notes, signed by Congress and made payable to the people. Failure to make good these promissory notes cannot help but breed disillusionment and discontent."

The Secretary concludes his point by saying: "Whether it is a gaping chasm between authorizations and appropriations; or passage of legislation that provides far too few tools to attack the problem it purportedly addresses; or legislation that promises something new and different, yet merely duplicates what already is on the statute books–such legislative over-promise starts out by building hopes, but ultimately undermines confidence in government."

What do we do? How do we escape from a situation which seemingly is so hopeless? To review completely the recommendations which Secretary Richardson makes in his paper would take a great deal of time. There are a couple of points, however, I would like to highlight because I feel they can and will directly affect you.

The Secretary perceives HEW's role as being two-fold, direct and indirect. Our direct role is one of administering a program in which sharing the responsibility would not be administratively feasible, such as the social security system. More important to you, however, is our indirect role–the role of providing logistical support for, as the Secretary has said, "the teachers, the healers, the social workers, and the rehabilitation counselors who are not employed by HEW, but by state and local governments and by private agencies. It follows that the success with which HEW carries out its indirect, supporting role depends on our effectiveness in backing up those who teach and heal and serve. *They* are the frontline troops. HEW's mission is to provide planning and logistical support. Our job is to help by identifying the needs to be met, to help by making sure that people who can make good use of better methods of providing services are made aware of them; by supplying financial support of such services; by increasing the supply of service providers where there are shortages; and by improving communications within the whole service system." This is basically how Secretary Richardson feels HEW can be most effective in responding to the needs of those whom we seek to serve, the American people.

He has already initiated several steps to achieve the goals described in his address. These initiatives include cutting away "that most ubiquitous outgrowth of program proliferation—the strangulating vine called 'red tape.' " Also included are grant consolidations, services integration and decentralization.

How does all of this affect you? Let's look for a moment at the Developmental Disabilities Services and Facilities Construction Act of 1970.

At the federal level, we have watched the weed-like growth of programs promoted by vested interest groups and patterned to meet the needs of members of a particular category, all the while failing to meet similar needs of individuals excluded from the program.

Hence, the Developmental Disabilities Services and Facilities Construction Act of 1970, represents a progressive step in programming because it reaches out to embrace disabled individuals with similar needs regardless of traditional categorical labels.

The D.D. Act is an amendment to the old mental retardation law (P.L. 88-164) and has basically strengthened the old law. However, before going into detail, let us review the situation from a historical perspective.

The mental retardation law was passed by Congress in 1963. In 1970 the developmental disability amendments (Public Law 91-517) became law. In the brief period since the passage of the D.D. Act, we have seen a natural progression in the expansion and, where necessary, a supplantims of the supplant in the 1963 law.

Not the least of the forces which led to the D.D. Act, was the impact made by the work of the President's Committee on Mental Retardation, federal grants programs, and the increased strength of voluntary agencies. The D.D. Act was an outgrowth of the studies made by the President's Committee on Mental Retardation, which revealed that conditions in some institutions were utterly deplorable. The problems addressed by the President's committee were size, overcrowding, understaffing, high staff turnover, low staff morale, high rates of absenteeism, and substandard basic maintenance care for the patients.

The mental retardation act of 1963 was aimed at Institutions where care was tantamount to warehousing of human beings. It provided for construction and remodeling of facilities and for improvement in care of the residents through demonstration projects and training of personnel.

Buildings were constructed; demonstration programs did improve care in institutions; and trained manpower proved more efficient.

The law had made some impact, but nowhere near enough progress had been made. There were significant problems with the law.

State planners complained that the old law was inflexible and that labels assigned to the functioning levels of retardates were proving transient. With increased attention given mentally retarded individuals, it was found that they could progress to a higher functioning level—even from the institution to the community. The focus for services was changing from institution to community, and the community demonstrated a greater willingness to accept the retardate. There were islands of success demonstrating what could be done with trained personnel, improved staff/patient ratio, improved services, and with more humane treatment of the retarded individuals. However, it soon became apparent that those people who were not mentally retarded, but developmentally disabled were not eligible for help under existing law. It was quite clear that a new law, or an amendment to the old law was necessary.

Thus, all of these impacting forces, together with a recognition of the inadequacies of the old law led to enactment of the developmental disability act.

The purpose of the D.D. Act is to bring more and better services at a quicker pace to those individuals substantially handicapped by a disability of neurological origin, beginning in childhood and expected to continue indefinitely. Mental retardation, epilepsy, and cerebral palsy, are specifically mentioned in the law, together with "other neurological conditions still to be named."

The thrust now is not at building bigger and better institutions, but rather preparing the developmentally disabled individual for independent or semi-dependent life in the community through habilitation programs. This is in the direction of strengthening the generic services and employment opportunities in the community. Hopefully, this new thrust can prepare these handicapped persons for the community *and* at the same time prepare the community for the handicapped.

The actual provisions of the D.D. Act are wholly in keeping with the social consciousness of the day and our efforts at programing towards human betterment.

The actual bill itself is intended to provide for the following:

A. Meeting the special needs of the disadvantaged, making an adjustment for poverty.

B. Setting aside money for use on special projects of national significance.

C. Special projects to demonstrate new or improved techniques in service delivery.

D. Strengthening university-affiliated facilities programs by adding support of new interdisciplinary programs in institutions of higher learning.

E. The law allows a co-mingling of federal developmental disability funds with those of other ongoing state programs.

F. And finally it provides for a state planning and advisory council responsible, as you all are well aware, for submitting revisions of the state plan and reports to the Secretary of HEW.

In the grant area, emphasis is put on formula rather than categorical grants to states. The formula is based on per capita income, population, and the need for facilities and services. Formula grants are made directly to state designated agencies which allocate the allotments to projects, whose priorities are determined by key people within the state. In essence, federal money becomes state money to be spent by the residents in pursuing the goals of *their own* comprehensive plan.

This change in the grant structure and addition of your council combined with other provisions in the D.D. Act has in effect shifted the focal point of our efforts to the local level where the handicapped individual should have his needs met, and to where the strength of the program should be. This new direction coincides directly with one of Secretary Richardson's key initiatives, improving the quality of services disseminated by HEW.

That initiative is decentralization, one which I have already alluded to. The Secretary has said: "If HEW is to be of maximum use to the frontline forces engaged in health and education and welfare services, we must not only make our support of those forces as adaptable as possible to community needs, but also to see to it that our support is as accessible as possible. It follows that our support functions must be moved up as close to the front as we can get them. This in turn requires that we place increasing reliance on our regional offices."

"Under the polite but persistent prodding of the Assistant Secretary for Community and Field Services, a number of concrete steps have been taken to strengthen the regional offices and accelerate the process of decentralization. For example, the newly established project grant review and control system gives the regional directors an opportunity to review and concur in selected centralized grants before awards are decided."

I have already mentioned cutting away the strangulating vine of red tape. The Secretary has said that, "Grant packaging, and grant consolidation will, separately and in combination, make federal support less hampering and more useful. They will help to bring about more comprehensive, less categorical service-delivery systems. But the fragmentation or services is by no means a consequence solely of federal policies and procedures, and it cannot be overcome by federal action alone." *This* is our challenge to joint action.

We in HEW need your help as much, if not more, than you need ours. Our charge is to create a lasting coalition to effectively improve the lives of the developmentally disabled. We now have significant, progressive legislation. We also have a department which is adjusting to meet the needs of the day. But we cannot do the job alone. Making our partnership work is a formidable task. As the Secretary has said, "We know how enormously difficult a task this is. We know how much remains to be done–how great are the needs of our fellow citizens and the demands for more money, more manpower, new ideas, new technology, better management, more efficient deployment of resources, and more responsive institutions."

"But we also know that in performing this task, we are bringing closer the fulfillment of the promise of America. It is still an inspiring promise. And if at times our progress toward it seems frustratingly, even agonizingly slow, there can be no greater reward for any of us than the satisfaction of playing a part in bringing it closer."

Thank you.

Fiscal Synergism: OMB in Advancing The Nation's Social Goals

Paul H. O'Neill

I am pleased to be here this morning because of the special opportunity your meeting affords to convey an understanding of the role of the Office of Management and Budget (OMB). Hopefully, in a way that will prove useful to you as you pursue your important goals.

A quick review of our history will help to illuminate our role, so let me begin there. The roots of the Office of Management and Budget go back to the passage of the Budget and Accounting Act of 1921. Before the passage of that Act, there was no executive budget as we know it today. The process was simple and chaotic. Each Department and Agency head prepared his own "wish list" and submitted it to the Secretary of the Treasury. The Treasury Secretary's function was limited to receiving, indexing, printing and transmitting the estimates to the Congress. This business occupied the time of one Treasury employee. In the course of debating the need for change in 1921, Congressman Good of Iowa enumerated the basic defects of this system. He said;

> ... "the estimates of expenditure needs now submitted to Congress represent only the desires of the individual departments ... these requests have been subjected to no superior revision with a view to bringing them

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Mr. Paul H. O'Neill, a Federal Career Executive, was appointed as Assistant Director of the Office of Management and Budget with specific responsibilities for Human Resources programs and certain government programs in 1972. Prior to his appointment, Mr. O'Neill was Chief of OMB's Human Resources Programs Division. He was graduated from Fresno State College with an AB in Economics. He received an MPA degree from Indiana University on completion of study as a Fellow of the National Institute of Public Affairs. He was awarded the William A. Jump award "for his exceptional ability in analyzing programs and issues" and for his "outstanding performance in carrying out very complex and demanding tasks involving the formulation and administration of Federal Human Resource Programs."

> into harmony with each other, to eliminating duplication or organization or activities, or of making them, as a whole, conform to the needs of the Nation as represented by the condition of the Treasury and prospective revenues . . . ."

There are three foundation stones for the O.M.B. in the Congressman's comments. The idea that some institution needed to be concerned with:

1. bringing agency estimates into harmony with each other;
2. eliminating duplication of organization or activities;
3. making sure the agency spending estimates conformed to revenue estimates.

These foundation stones were put into place on June 10, 1921, when the Congress passed the Budget and Accounting Act establishing the Bureau of the Budget in the Treasury Department. In 1939 the Bureau was moved to the newly created Executive Office of the President and on July 1, 1970, The Budget Bureau was replaced by the Office of Management and Budget.

So much for organization history. Let me turn now to process, using the calendar as a framework.

The law requires that the President submit his budget to the Congress within 15 days after the Congress convenes. This year the budget was submitted on January 24. Following transmittal of the annual budget document, the OMB staff typically has a heavy involvement in the preparation of the legislative program. This OMB function is perhaps less well known than our budget activity, but it is no less important. OMB plays a convener role for the President in this process. We have a staff of people who are responsible for assuring that all interested agencies have an opportunity to state their views on potential legislation through the complete cycle of the legislative process. There are several key points in the process where this activity takes place:

1. when the Administration is developing its own legislative proposals;
2. when the Congress asks for the Administration's views on a bill introduced by a member of Congress;
3. when Administration spokesmen are asked to testify before a legislative committee; and
4. when the bill is before the President for action.

During the last part of January, through the middle of March, this activity consumes significant amounts of OMB staff time.

While the legislative clearance process is at its peak in the early months of each year, OMB staff is also engaged in the execution phase of the budget program.

During the months of February, March and April, field visits are made to see programs in operation, to talk to community leaders, to scholars and interest groups about problems and prospects for conducting the Federal business in a more productive way.

Overlapping this period and reaching into the months of June and early July, we begin our preparation work for the next presidential budget. This activity is centered around a process we call Spring Preview.

This process has two intermediate objectives:

- development of a series of budget projections, that indicate prospective revenues and expenditures, by agency and activity, over the next five years;

- identification of problem areas that will require Presidential attention in the Fall.

The ultimate objective of the Spring Preview is to obtain Presidential decisions on planning figures to be used by the Departments and the Agencies as they prepare their budget requests and to assign responsibility for staffing out optional ways of dealing with potential problems.

Presidential planning figures for the forthcoming budget year are communicated to the Agencies in mid-July. During the last half of July and the month of August, OMB staff again focuses attention on budget execution activities and the legislative process.

On the first of September, agency budget requests begin to arrive. Ideally, from that point until the budget is sent to the Congress, our work is dominated by budget preparation. I say "ideally" because over the last several years Congress has remained in session far into the Winter, sometimes taking only a Christmas recess between the end of one session and the beginning of the next. Under these conditions our attention is necessarily divided between the budget and legislative processes.

When the agency budget requests and supporting justification materials are in hand, we begin our fall budget review.

The fall review has several major stages. The first step involves a detailed examination of the agency request which produces an agenda of questions for discussion with the agency.

The second stage of the review consists of a series of meetings with agency officials; usually starting with program managers and ending in a meeting with the Secretary or Agency head. These meetings are designed to gather all of the supporting justifications for the agency proposals.

Following these meetings, OMB staff prepares a series of books; one for each major agency and several that cut across agency lines. These books contain basic budget trend-line information, classified by program function and activity. The budget information is supported by issue papers, setting forth for example:

- alternative funding levels;
- the potential impact of alternative funding levels;
- information on program accomplishments since the inception of the program and during the most recent program year;
- the target population for the program;
- the size of the target population being reached by the program, etc.

The books provide the basis for the next stage in the process; Director's Review.

Beginning in mid-October and continuing through mid-November, sessions are held with the OMB Director, his Deputy, and Assistant Directors to review and discuss with the examining staff all of the information collected and analyses prepared.

Following these sessions, summary books are prepared for the Director's discussions with the President. These discussions overlap the Director's Review schedule and produce presidential program and budget decisions. These decisions are communicated to the Department and Agency heads and the next and final step of the OMB's work begins–preparing materials for printing.

Typically, the printing presses begin to roll in late November. During the six-week period ending in mid-January we produce:

1. *The Budget;* a 600-page compilation of the budget plan;
2. *The Budget-In-Brief;* a 90-page summary of the budget plan;
3. *The Appendix;* an 1100-page document containing detailed information for every budget action proposed to Congress;
4. *The Special Analyses;* a 300-page book containing 20-30-page summaries of major program areas, e.g., health, education, housing, etc.

In mid-January the President transmits his budget to the Congress and the cycle begins again.

Throughout the budget cycle, OMB is also performing its "Management" functions. These functions take many forms. Perhaps the most formidable task undertaken by the Office in its management capacity has been our work on the President's proposals to reorganize the Executive Branch of the Federal Government. As you may know, these proposals would consolidate the domestic executive departments and a number of independent agencies into four new major purpose departments.

Management activities that have received less public notice include preparation and follow through on proposals to create the Environmental Protection Agency, the Special Action Office for Drug Abuse Programs, and the consolidation of the Peace Corps, Vista Volunteers and several other agencies into the Action Agency.

Our day-to-day management activities include clearance of forms proposed for use by Government Agencies, their contractors and grantees; and, Government-wide policy guidance for automatic data processing activities.

Implementation of policy and special management assignments from the President have also become major activities of the Office over the past few years.

Examples include working with a task force of agencies to insure job and training opportunities for veterans, and temporary assignment of the Deputy Director of OMB and several staff members to coordinate Federal disaster relief activities in Pennsylvania in the wake of Hurricane Agnes.

You may be interested to know how many people perform our management and budget work and what types of backgrounds they have.

In Fiscal Year 1973 we requested funding for 655 permanent positions. Of this total approximately 325 are professional staff. The remainder are support personnel.

The education and experience backgrounds of the professional staff are quite varied. For example, we have people with degrees and experience in law, economics, political science, sociology, history, international relations, mathematics, chemistry, civil engineering, bio-physics–practically every academic discipline.

Having covered briefly, organization history, the budget cycle, management functions and personnel aspects of the OMB, I would like to turn to OMB's substantive role, using the budget as a context.

As you probably know, our spending target for Fiscal Year 1973 is $250 billion. From a fiscal policy point of view, that $250 billion number represents our best estimate of the number of dollars that would be produced by our tax system with full employment.

From a program point of view, the $250 billion number represents the dollars available for financing all Federal activities.

In my experience, there is one certainty; ideas for spending always exceed available revenues. That may sound unbelievable when coupled with a $250 billion number, but when you begin to look at the parts that make up the total, it becomes more understandable. When we *began* our planning for the Fiscal Year 1973 Budget, slightly more than 70 percent of the $250 billion total was, for all practical purposes, already spent. Items such as, benefit entitlements to Social Security, Veterans payments, and Medicare; coupled with payments for contracts already let and interest on the public debt predetermined $175 billion of spending.

Under these conditions it is clear that there must be a decision process for allocating resources and that is where the OMB's substantive work begins.

We approach our task from several different perspectives. First, from the perspective of the Federal Role. When someone has a new program proposal for Federal funding or when we are going through our annual reviews, we are constantly asking; why should the Federal Government be doing this. The obvious reason for this question–to keep Federal spending down–is not in my view the only reason. Nor is it the most important.

Over the last several years we have begun to learn something very significant. That is, Federal spending may not produce the desired objective because of adjustments by other institutions in our society or because of capacity limitations.

In other words, the simple addition of program dollars to the Federal budget may not lead to a net addition to the Society's total effort. If we increase Federal spending, and State and local governments and private institutions decrease their own, our only success has been to funnel more of the GNP through the Federal budget process. The capacity limitation problem is also an important constraint. An example highlights the problem. In the mid-1960's, the Congress enacted and we began to fund a series of scholarship and fellowship programs for medical students. The goal was simple and straightforward to increase the number of doctors in the country. Unfortunately the analysis of the problem was not complete. The premise of the program was that there were spaces available in medical schools which could be filled if only there were funds available to help needy students attend. In fact, something close to 50 percent of the qualified medical school applicants were being turned down simply because there was no room for them.

A second OMB perspective deals with how a goal can be best achieved. From this perspective we examine alternative intervention mechanisms, including: (a) cash grants, (b) contracts, (c) tax subsidies, and (d) regulatory actions.

From a third perspective we examine questions of balance. This perspective can be best demonstrated by reference to a specific program area. For example, the health area. In Fiscal Year 1973, the Federal Government committed $25.5 billion to health programs. These funds were distributed to six major categories: (1) health research, (2) training and education, (3) construction, (4) direct Federal care, (5) health care financing programs, such as Medicare and Medicaid, and, (6) prevention and control activities.

While we examine each of these areas in detail, we also consider their interrelationships. For example, we look at the relationship between funding for health research and funding for training health researchers.

A fourth perspective is the efficiency dimension. We are constantly looking for new ways to increase the amount of the product that can be produced with the same or fewer dollars. Associated with our efforts in this area is our continuing push to stop doing things that no longer make sense so we can make room for things that do need to be done. For example, we continue to push for modification of the so-called impacted area aid program—a program that provides Federal funds to my school district because I happen to be employed by the Federal Government.

Hopefully, these perspectives will give you a general idea of the way we approach our work.

I would like to turn now to two final topics: the role of your Councils and prospects for the future.

First, on your role—in my judgment, the work of your Councils, and groups like yours is destined to become increasingly important. I make that statement with two thoughts in mind. First, it is apparent that we cannot afford the waste and inadequacy associated with fragmented services; nor can we in Washington overcome the problem of fragmentation alone. We can make it easier for you to pull things together at the delivery level by broadening the forms of assistance, but we cannot make it happen. If this premise is correct, then there must be an integrating mechanism at the state and local levels.

The second thought is really a statement of experience. Over the last several years, as I have worked with human resources programs, I have observed an interesting phenomenon. Each Department and agency is continually trying to define its mission in a broad enough way to encompass the needs of people as individuals. Housing program officials urge health services and education. Education program officials urge feeding programs and income assistance. Health program officials urge education and housing. They are all saying the same thing—the problems of people do not fit into neat categorical boxes.

With the combined pressures, what are the prospects for the future? The experience of the last few years is worth noting. While the last few years may have been perceived as "tight budget times," in fact, spending for human resources programs has increased dramatically. Not only in absolute terms, but in relative share of the budget total. In Fiscal Year 1970, spending for these programs was $72 billion. The budget for 1973 contained $111 billion for these same programs. A $39 billion increase in four fiscal years.

The change in relative shares is equally large. In Fiscal Year 1970, human resources programs comprised 32 percent of the budget. In 1973, these same programs accounted for 45 percent of the budget.

These figures do not include the amounts budgeted for revenue sharing. In my estimation, the $32 billion in revenue sharing funds that are going to be distributed to your state and local governments over the next five years (over $8 billion in the next eight months alone) represents the biggest opportunity and challenge you will face in the near future–an opportunity because at last there will be a large pool of funds available that can be used to deal with the problems of developmental disability–a challenge because you will have to work with your state and local governments to convince them of the high priority of your efforts.

In summary, I would assert that the need for your role is self-evident and the opportunities for success are boundless. As you complete your conference and turn to the opportunities and challenges before you, I wish you the very best of luck.

Part II
Planning and Evaluation

Editor's Notes

The Developmental Disabilities Act stresses the importance of careful advanced planning and continuous evaluation of the product of service. This emphasis on activities which often receive short shift in the life of the harried service program administrator constitutes a recognition of the central role planning and evaluation must play in the establishment of a well-rounded program for developmentally disabled children and adults.

The severity and chronic nature of developmental disabilities sets them apart from most other health or health-related conditions. Every aspect of the afflicted individual's life is affected and his needs for services are often multiple over a period of many years. Thus, the challenge facing an individual, a family, a service agency, a state or the nation in dealing with the developmentally disabled is to marshal the proper mix of health, social, educational, rehabilitation and habilitation services needed by the developmentally disabled over a period of time. This is not an easy task given the fragmentation in society's present system for delivering human services. Yet, it is an essential task in order to fully meet the needs of the developmentally disabled. For this reason the planner of the Developmental Disabilities legislation viewed the Act as a mechanism for identifying existing gaps in services to the affected population and finding ways of filling these gaps.

Recognizing the crucial importance of planning and evaluation in mounting an effective state or local program, the conference planners commissioned a series of papers on the subject. Each paper included in this section of the proceedings tends to view the process of planning and evaluation from a slightly different perspective; yet, the authors all share a common belief in the importance of effective and continuous planning and assessment of the outcome of programs.

Frank Laski conceptualizes four levels of planning contemplated under the Developmental Disabilities Act: (1) the review, evaluation and updating of state DDSA plans; (2) operational planning; (3) comprehensive, rational planning; and

(4) leadership planning. He suggests that leadership planning, with its stress on galvanizing a wide variety of specialized and generic agencies into action, appears to be a planning approach which many state agencies and advisory councils are desirous of adopting. He also points to the trend away from comprehensive planning efforts in the field of human services and a corresponding thrust toward service integration. In Laski's view, the future of the Developmental Disabilities program will rest on how successfully the program can adjust to the emerging trend toward human service integration.

Anthony J. Arangio warns that establishing plans and setting priority frequently is not a simply, straightforward and rational choice among alternative strategies. In his words, "priority setting is at times . . . an opportunistic, value-laden, power, politics process." He debunks the sophisticated jargon of planning and demonstrates that, consciously or unconsciously, we all engage in the planning and priority setting process everyday. The importance of the way in which planning questions are formulated is also stressed. Arrangio suggests that we openly acknowledge that competition exists between the actors involved in the planning process; such openness on the part of all parties, he feels, will make it easier to find a common meeting ground. The paper also contains a helpful checklist to follow in planning and priority setting.

Leopold Lippman suggests several factors which the community or state level planner must take into account including: (1) the population in need of service (e.g. demographic trends, changes in types and degrees of disability, and rising and declining prevalence rates); (2) changing techniques and patterns in service delivery; (3) shifts in public attitudes; and (4) the interrelationship of program elements in the service delivery system. He argues cogently for a blending of the unique talents and resources of professionals, parents, consumers, volunteers, public agencies and private organizations in an effective planning process and suggests several places where the planner might turn for help. Lippman also reviews some of the communication tools available to the planner and warns against local insularity and losing sight of the long range implications and spin off effects of planning decisions.

Michael J. Bednar focuses our attention on an area of planning which, until recent years, has received little attention–i.e. the physical environment in which the developmentally disabled individual lives, works and plays. He stresses the need to program environments which are responsive to the needs of the developmentally disabled. Emphasizing that the physical environment has a profound effect on man's well-being, he identifies three special problems faced by the developmentally disabled: (1) perceptional difficulties; (2) motor limitations; and (3) psycho-social handicaps. Bednar goes on to delineate 10 sets of environmental characteristics which relate to the needs of the developmentally disabled. Although the ultimate goal is to tailor the environment to fit the individual, the writer recognizes that because of changes in program concepts, alternations in individual needs and the disparity between the needs of the group and the needs of the individual, a perfect "environmental fit" probably is not feasible; therefore, he suggests that architects must learn to design flexibility into future structures.

Donald J. Stedman and Richard C. Surles sketch out a model planning and evaluation system and describe a hypothetical situation to demonstrate how the system might function in practice. A distinction is drawn between goals, administrative objectives and outcome objectives. The authors also outline the differences between process and product evaluation and show how evaluation differs from research

Specific strategies and approaches to program evaluation are discussed by Seldon P. Todd. After defining what constitutes evaluation (as distinct from evaluative research) and delineating five categories of evaluative studies, Todd suggests several possible uses for evaluation from the point of view of state DDSA advisory councils. He also proposes five fruitful areas for evaluation and concludes with several practical suggestions on how much to spend, how to conduct evaluative studies on a "shoe string" and ways of locating other sources of support for DDSA evaluation projects.

In the final analysis, the effectiveness of any program for the developmentally disabled must be judged on the basis of its ability to produce measurable change in the intellectual, motor, perceptual performance and adaptive behavior of the clients it serves. Eyman, Tarjan and Keeran describe elements necessary to development of an effective individualized data system which can be used to assess client progress and evaluate agency performance. They note the dirth of client date systems presently available and trace the history of their efforts and that of their colleagues at Pacific State Hospital to improve client data over the past 20 years.

The Planning Process for The Developmentally Disabled

Frank J. Laski

The purpose of this paper is to stimulate discussion concerning the planning process for the developmentally disabled. The Developmental Disabilities Program involves a wide range of issues relating to planning – various approaches to planning; use of specific planning techniques; the development of goals, objectives and criteria for plans. This paper will attempt to raise these issues by focusing on clarification of the planning responsibilities of the State Planning and Advisory Councils; comparing the planning responsibility to other statewide planning experiences, and examining the potential for successful planning on behalf of the developmentally disabled, especially in relation to the concept of leadership planning.

The importance of planning is clearly set forth in the Developmental Disabilities Act. The purpose of the Act speaks first to the need for "developing and implementing a comprehensive and continuing plan for meeting the current and future needs for services to persons with developmental disabilities."[1] Other provisions refer to the State Planning and Advisory Council's duty to review, update and revise state plans and assure effective ongoing state planning. In addition, the law enumerates throughout various sections a number of planning techniques (statewide inventories, surveys of need, priority setting, etc.) The rules and regulations under the DD Act reinforce the central role of planning and pinpoint the responsibility of the State DD Councils "to provide leadership in planning and evaluation."[2] The regulations also stress the interagency aspects of planning and the need to coordinate with other state-federal plans.

Despite the legal mandate for planning and the regulatory requirements relating to planning, the generality of the concept and the lack of clear understanding as to the structure, strategies and techniques for planning, allow the states a wide variety of options in carrying out their planning responsibility. In fact, the states may claim to undertake planning by engaging in four distinct levels of activity.

The first level of planning involves activity related to submission and update of the state plan. While in most cases, the Developmental Disabilities State Plan is simply an administrative control device used by the federal government to document the contractual arrangements for receipt of funds, a few states (e.g., Massachusetts and Ohio) have utilized state plans as comprehensive planning documents.

At a second level, a state may engage in planning to the extent of developing short term operational strategies to allocate its resources, fund projects, and provide services.

Thirdly, a state may embark on a comprehensive planning effort with the goal of developing a comprehensive and rational system to meet the needs of the developmentally disabled. These planning projects are characterized by an interagency, multi-program focus; rational deliberations to formulate goals and objectives; acquisition of data; and development of need-resource indicators and sophisticated techniques for determining priorities. The plan itself is viewed as an aid for decision-makers and a rationalizing influence on programs and policy for the developmentally disabled.

Comprehensive planning may be followed by a fourth level of planning–leadership planning. As described by Binstock, leadership planning involves leading the total system to meet the needs of the developmentally disabled.[3] The statutorily derived components of leadership planning include coordination of services, planning and evaluation, data gathering, liaison and cooperative relationships. Other elements include advocacy and community organization.

The particular relevancy of leadership planning to developmental disabilities has its roots in the 1958 findings of the Council of State Governments, and the 1962 report of the President's Panel on Mental Retardation which highlighted the need for coordination of generic and specialized agencies serving mentally retarded persons. The interagency approach was subsequently extended to the developmentally disabled and codified by the DD Act; this approach involves encouraging designated state agencies to assist generic and specialized agencies to change existing policies, priorities, and operations in order to provide improved services to the developmentally disabled. Binstock gives a number of examples of leadership planning activities well suited to interagency concerns. These include enactment of legislation, influencing executive budget priorities, securing allotments and services for the developmentally disabled in other state plans, and reorienting institutions to community outreach. A number of other activities (with the exception of short term service provision) may be considered as leadership planning as long as they involve a strategy of securing changes in laws, policies, administrative rules, organizational structure and operations for the benefit of the developmentally disabled.

At first blush it would seem that the above formulation of planning is all encompassing and includes a number of elements heretofore characterized as social action. However, it is important to understand that the leadership planning concept does deny the planning/action dichotomy and instead promotes the idea of a planning-implementation continuum (i.e. that implementation begins when initial planning decisions are made). In addition, it would seem that leadership planning assumes a certain conceptual framework regarding service delivery (effective, coordinated, accessible, continuous) and a commitment to ideological planning.

To recap, states and State Planning and Advisory Councils may be involved in four levels of planning: (1) review, evaluation and update of State Plan, (2) operational planning, (3) comprehensive rational planning and (4) leadership planning. While it has been stated that all four levels of planning are required by the Developmental Disabilities Act and regulations, current federal policy provides the states a great deal of latitude in terms of level and quality of planning activities. Certainly, no state is in danger of losing federal funds for failure to undertake leadership planning. Nevertheless, there is evidence of state agency *intention* to play the role of change agent for the developmentally disabled.[4] Given the predilection to undertake leadership planning, questions concerning states' capacity for leadership planning and the ways and means of successful leadership planning become central to implementation of the Developmental Disabilities Act. However, before addressing these questions directly it is helpful to gain some perspective by looking back on prior human services planning efforts which bear some similarity to developmental disabilities planning.

In the 1960's a succession of statewide planning efforts were fostered by the federal government to stimulate states to plan for human service needs. These statewide planning efforts (mental health; mental retardation; vocational rehabilitation; comprehensive health) were all similar to developmental disabilities planning especially in terms of: (1) responsibility for planning (state agency, usually an agency with operating responsibility for categorical program); (2) participation in planning (broad based planning boards and councils, interagency-consumer constituency participation; consensus orientation) and (3) federal quality control of planning (none). The major differences between preceding statewide planning and DD planning are the time limited nature of statewide planning (except comprehensive health) and the lack of control of federal service monies by planning units.

Reviewing the statewide planning efforts of the sixties in terms of leadership planning and basic changes in the service systems is not encouraging. The problems which gave rise to the need for intensive planning–unreliable or non-existent data; fragmented services; ineffective program–still existed years after plans were filed away. Even as planning efforts were underway new public programs proliferated the service system and specialization and categorization increased. Upon an extensive analysis of the statewide planning approach one student has concluded, "Statewide planning contributed to the perpetuation of existing power configurations permitting incremental change–forestalling fundamental challenges."[5]

Even in those states where planning efforts did result in significant changes in law and executive reorganization of mental health and mental retardation services, planners acknowledged the limitations of categorical planning and the dangers of opportunistic domain expansion through manipulation of "comprehensive" planning.[6]

The reasons for the lack of impact of statewide planning should be of concern to Developmental Disabilities planning units. While a number of reasons could be advanced, one hypothesis should be examined closely in terms of its implications not only for the states but also for the RSA. This is the contention that the negative results of statewide planning were generally guaranteed by federal preconditions and guidelines (or lack thereof) which opted for a conservative stance in organizational placement of planning under the control of operating agencies, which fostered a consensus orientation based on interest group liberalism, and which placed no demands on planners in terms of quality or evaluation of plans.

The similarity to Developmental Disabilities bears reiteration. The regulations on state agency placement and State Planning and Advisory Council composition are direct descendants of P.L. 88-156 requirements. Thirty-two Developmental Disabilities units are within the Department of Mental Health or Mental Retardation. Most DD executives are appointed by bureaucratic superiors and are responsible to hierarchical superiors within the operating agency. State Planning and Advisory Councils are dominated by state operating agency representatives. No federal guidelines for planning exist. While Binstock's data is inconclusive regarding organizational placement and composition of the councils, his work with Councils for the Aging indicates that units located at the first hierarchical level (i.e. direct access to the Governor) are more likely to pursue systemic reallocation than units within state departments.[7]

The fact that Developmental Disabilities planning shares some characteristics with unsuccessful statewide planning does not mean that it must have the same outcome. An important distinction is the ongoing nature of developmental disabilities planning. This feature, in contrast to the time limited, mental health, rehabilitation, and retardation planning efforts, allows the federal government to develop guidelines which encourage states to develop common objectives and confront basic issues of care and service delivery. It allows for the evaluation of planning procedures and for the provision of technical assistance in leadership planning. Perhaps most importantly, the continuing nature of the program allows for basic changes in the planning structure through legislative amendment or administrative initiative.

The second feature which distinguishes developmental disabilities planning from the previous planning is the direct relationship to federal funds to finance direct services. However, the availability of money to fund projects and provide services is a two edged sword. On one side, it may be used to lower barriers to the developmentally disabled, access services, tap other funding sources and generally provide leverage to implement planning objectives. On the other side, it may divert attention from planning functions to services, hamper coordination, and promote competition among constituents of the State Planning and Advisory Council. Although there is a great need for increased funding of many services for the developmentally disabled, it is not inappropriate to ask whether significant increase in service monies channelled through Developmental Disabilities units would be parasitic to leadership planning. The experience of the Law Enforcement Assistance Administration provides a case in point. One leading expert contends that federally funded state planning agencies in the field of criminal justice accomplished, at a cost of one half billion dollars, exactly what our other statewide planning activities accomplished–preservation of the status quo.[8] Consideration of the promise of developmental disabilities planning in the context of past planning efforts leads directly to three key questions concerning leadership planning and developmental disabilities.

1. What is the role of the State Planning and Advisory Council in leadership planning?
2. What are the prerequisites for leadership planning and how can states develop the capacity for leadership planning?
3. What leadership planning strategies are available to state Developmental Disabilities units?

These questions can only be properly addressed at the state level and should be of concern to each State Council. However, some observations can be made based on limited survey data and the discussions at the National Conference.[9]

The attitude of the State Council toward influencing the policies and resources of its constituent public and private agencies, and the role the Council takes in pursuing leadership planning are essential to the Developmental Disabilities concept. Each State Council has the potential to be a powerful change agent at the state level. Yet, despite much discussion on the role of the State Council, its membership, staffing, location and internal organization, there is no agreement on a formula that can be applied to develop leadership planning oriented Councils in all states. On the contrary, it has been suggested that no model is possible, since the role of the State Council in leadership planning is essentially directing and wielding political power for the purpose of achieving specific planned objectives for the developmentally disabled. In each state the planning objectives will be different; the Developmental Disabilities power structures will be different and the external political system will be different. Thus, in one state consumer domination on the Council, or direct access to the Governor's Office, may be important. In another state, the political environment may require a statutory base for the Council and a close working relationship with the legislature. What remains constant in all states is the requirement that the Council set clear goals to provide a planning framework for its activities and make a commitment to ideological planning–i.e. a commitment to attach the status quo.[10] With planning goals and objectives, and a commitment to change, the approach, strategies and techniques of leadership planning appropriate to each state will fall into place.

In addition to a strong State Developmental Disabilities Council, a number of elements have been identified in various states as vital to developing the capacity to undertake successful leadership planning. Among the most prominent factors are: (1) an investment in planning, (2) independent planning staff, and (3) regional planning capability.

A review of expenditures and program priorities reveals that about two-thirds of state Developmental Disabilities activities are primarily concerned with direct services and benefits to clients. While some of the service activities are undoubtedly planned to influence and achieve general improvement in the service system, the high concentration on services may indicate that many states have not seriously considered the need for a major commitment to and investment in planning. The magnitude of the planning investment is a decision for each State Council and will vary from state to state. Some State Council members have taken the position that current appropriations preclude effective service provision (gap filling or otherwise) and that planning is the only viable DD activity.

Related to the planning investment is the staff available to the State Council for planning. Council members have expressed frustration in relying on state agency staff and outside consultants to develop planning strategies and implement planning priorities. The problem is evident when one considers State DD Council planning goals targeted on the state agency which in reality controls "Council staff." Again, conditions vary from state to state and some Council-Agency relationships may have developed to the point where control of staff is not an issue. Nevertheless, it would seem that the more independent staff capability the Council possesses the more it will find itself in the position of being a Planning and Advisory Council rather than merely an advisory council.

Regional planning capability has been addressed by DD Councils in a few states and deserves more attention with the advent of general revenue sharing and the possibility of major special revenue sharing proposals in health, education and social services. Many states are developing regional approaches to planning and a delivery of a broad range of services of importance to the developmentally disabled. Public education has been identified as a system most susceptible to influence through local and regional planning. The extent to which a State Council becomes involved in regional planning depends somewhat upon the degree to which resources and services are controlled at the local level, and the mechanisms available to the Council to influence local planning decisions. In developing regional planning capacity, maximum use should be made of existing regional boards and planning units. Some states are considering adding DD staff to mental retardation planning boards and other local structures. Minnesota, for example, has attached staff to the local planning development commissions in the state.

With a commitment to leadership planning, resources allocated to planning, and staff capability at state or regional level, the State Council may undertake a variety of leadership planning strategies. Among those available and receiving most attention in the states are: (1) Planning and demonstration projects, (2) Advocacy; and (3) Influencing Executive Branch Agencies.

Rather than fund service projects as ends in themselves, many states are funding planning and demonstration projects specifically designed to stimulate activity on the part of other agencies. By concentrating on a particular client group (e.g. multiply handicapped or rural poor) or a particular service (e.g. transportation), the Developmental Disabilities agency attempts to demonstrate the feasibility and value of given service models and to create the opportunity for implementation of DD planning objectives by another agency.

Advocacy, as a planning strategy, can be directed at various targets: community organizations; professionals and local services providers; the legislature. Councils in states with strong voluntary associations and effective local community support for DD programs may work in concert with existing groups to apply pressure directly on the legislature and executive policy makers.

In other states where the DD system is not as strong, the approach may be to assist in the development of community organizations and citizen advocates or to embark on public awareness programming to undergird future legislative and program objectives (e.g. deinstitutionalization). The Montana State Council has adopted a noteworthy approach to the advocacy strategy by directly funding special DD staff to serve the committees in the Montana legislature dealing with DD legislation.

Influencing other state level agencies to allocate resources for the developmentally disabled is the best understood and most commonly involved leadership planning strategy. State Developmental Disabilities executives have indicated an intent to tap other public agency funding to finance about two-thirds of their DD program priorities. The parallel strategy of influencing other state plans, policies and regulations has also been pursued, and the process facilitated by the development of the *Guide to Federal State Plan Review.*[11]

Significantly, state welfare agencies have been the most frequent target of DD agencies seeking other funding sources, and Titles IVA, XIV, XVI of the Social Security Act the source of support, especially for day care and community programs. In view of the current ceiling on social services and the probability of restrictive federal regulations on use of social service funds, state DD agencies will find it more difficult to influence social service budgets, and will have to turn to a much more complete analysis of other funding sources. Also more attention will, by necessity, be devoted to influencing regulations which may not yield direct funding payoffs for the DD agency.

The widespread intent to undertake leadership planning in the states, the various capacity building efforts and strategies developed thus far, and the genuine interest of State Councils (especially consumer representatives) in the concept, all tend to indicate that State Developmental Disabilities Councils will be effective planning bodies. On the other hand, the failure of past categorical planning is lurking in the background and the direct service-planning competition does exist. Whenever service provision and planning are combined the fragile nature of the planning process must be taken into account. It is always easier to begin a new service or fund a new project than to undertake leadership planning with respect to an existing agency's programs or policies. The conflict can be avoided by establishing goals and objectives amenable to leadership planning strategies, and allocate service funds in relation to those goals and objectives. Ohio's state plan, which sets forth the objective of resource development as opposed to direct service projects, is an excellent example of the use of service money in the context of leadership planning.

Whether states can successfully undertake leadership planning should not be based on any particular similarity or dissimilarity with past statewide planning, or upon the DD experience to date. Perhaps the overriding consideration is capability of State Planning and Advisory Councils to adapt to an evolutionary shift in the federal-state human services planning approach. A case may be made that the statewide planning approach of the sixties has been abandoned and is yielding to an allied services planning approach.[12] Interagency coordination, with its strategies of increased communication, line agency cooperative agreements and public-private participation is being replaced by services integration, with emphasis on a multi-program focus, funding transfers, local planning input and strong gubernatorial control. Revenue sharing and consolidation aspects of the HEW Mega Proposal are variations on the same theme. As the states respond to the allied services thrust, we can expect the growth and strengthening of state umbrella human services agencies, greater planning capability by Governors and local governments and the consequent weakening and ineffectiveness of categorical planning within line agencies.

Fortunately, as pointed out in the foregoing pages, developmental disabilities planning, while having elements in common with categorical statewide planning, has a great deal of flexibility in law and regulations and is in a position to take advantage of the federal allied service thrust. Indeed, Ohio's DD zonal system, Massachusetts mental health-retardation area system, and California's regional centers concept, all provide examples of DD involved planning which has anticipated the importance of services integration as well as leadership planning. However, for many other states basic decisions and commitments concerning developmental disabilities planning still have to be made. These decisions will in large part, determine whether Developmental Disabilities is looked at a decade hence as the last of the categorical statewide planning attempts or the progenitor of allied services planning.

FOOTNOTES

1. Section 130(a), P.L. 91-517.

2. Ibid.

3. See generally Binstock, Robert, *The Role and Functions of State Planning Systems:* Preliminary Report on A Nationwide Survey of the Developmental Disabilities Program. SRS Grant No., 93-75174/1, March, 1972.

4. The Binstock study identified in 89 planning priorities of state DD executives which indicated intention to attempt leadership planning. Only 9 of the executives had no leadership planning goals. In addition, 33 of the 46 executives interviewed verbalized leadership planning goals.

5. Melia, Richard P. *An Ideological Analysis of the State-Wide Planning Approach in Four Health Areas,* (unpublished), October, 1972.

6. Demone, Harold and Newman, Edward, "A New Look at Public Planning for Human Services," *Journal of Health and Social Behavior,* Volume 10, No. 2, June, 1969, p. 146.

7. Binstock, Robert, *The Roles and Functions of State Planning Systems: A Preliminary Report on a Nationwide Survey of State Units on Aging,* SRS Grant No. 93-P-75174/1, March, 1972.

8. Vorenberg, James, "The War on Crime: The First Five Years," *Atlantic,* Volume 229, No. 5, May, 1972.

9. In addition to the National Conference workshop sessions, the material on leadership planning capability and strategies draws on the Second Report (D-2); Third Report (D-3) and Fourth Report (D-4) of *The Role and Functions of State Planning Systems.* SRS Grant No. 93-P-75174/1, February, 1973.

10. See Demone, Harold, "The Limits of Rationality in Planning," *Community Mental Health Journal,* I (1965), p. 380.

11. *Guide to Federal State Plan Review.*

12. The Allied Services Act. H.R. 15856, 92nd Congress, Second Session is intended to provide the statutory base for this approach. See Richardson, *Responsibility and Responsiveness: The HEW Potential for the Seventies:* DHEW Publication (OS) 72-19., p. 20-22 for the rationale.

Priority Setting in the Planning Process

Anthony J. Arangio

It would be rather remiss of me to not relate to you the mini-struggle I encountered while preparing this paper. It would also be rather unwise since the struggle I refer to can lead us directly into our topic for today—"Priority Setting In The Planning Process."

Our discussion is intended to stimulate you to consider the processes I consider to be pre-eminent in planning rather than just the mechanical "follow-a-checklist" process.

When asked to prepare this discussion several weeks ago, I knew immediately how it would sound and appear—at least I thought so. I reacted based on a practiced instinct. After all, I am supposed to be an expert in planning and administration.

However, once my private bout with self-indulgence and omniscient behavior subsided, I set to the task of organizing myself for this very moment. I found, as I relate below, that the task was not an easy one.

Allow me to give you a list of the many thoughts I had to consider:

I. What direction do I have from those who arranged this conference as to their needs?
    A. What subjects do they deem most important?
    B. At what level do they want material delivered – Theoretical? Abstract? Practice?
    C. What structural limitations do they impose?
        1. Time limits for presentation.
        2. Length of paper.
        3. Due dates.
II. What do I know about the topic?
    A. What do I want to include?
    B. What personal biases are going to enter into discussions?
III. What do I know about the anticipated audience?

A. Should material be at a theoretical level or practical level? (Or the age-old ploy of the planner—something of both!)

B. Should topic include examples based on the legislation for Developmental Disabilities?

C. If so, should all three areas of retardation, cerebral palsy, and epilepsy be used?

D. What does the audience want? Do they want "How to" information, "How did you do it" information, or catalytic thoughts?

IV. What do I know about the panel?

This was especially difficult or, for that matter, easy since the panel had not yet been chosen.

For those of you in the audience who are ready to lock me up as an incurable obsessive-compulsive, I must report that the list I just described remained, for a while, jumbled in my head. It was not the neat package portrayed above.

If we now consider the topics above and put our discussion in the framework of this author's desire and pressure to do a good job, we will begin to see what choices based on priority setting might have taken place.

I. We have three sets of actors to please or to at least consider.

A. The sponsors of this conference who asked me to speak—the sanctioning body.

B. Myself—the planner agent-liaison between the sanctioning body and you.

C. You—the consumers of the product. The recipient of that which the sanctioning body wants to sell you—as interpreted through myself—the agent.

Now, we ask ourselves the following question: *Whose needs take priority?*

The Sanctioning Body's Needs.

The sanctioning body is footing the bill for this conference—an important consideration. What they have set out as the topic description in the program brochure should be adhered to.

Certainly the content of all the talks during this conference and the titles thereof were decided after long and deliberate priority setting—or were they? We might ask how the need for the program and its content came about? Were consumers asked for consultation in the design of this conference? Surely in this day of emphasis on consumerism at the federal level of funding—they were.

Speaker's Needs.

What about me? What are my values and needs? Do I really care about what others think as much as what I think, or are my own preference priorities the "right" ones?

Am I going to take the parental attitude "I know what is best and I'm only doing it for your own good"?

The Audience-Consumer Needs.

Is the consumer's attitude and stance "I am here to learn," or "They're not going to teach me anything I don't already know," or "When I get the chance, I'm really going to impress sanctioning agents with what a good job we are doing in X, Y, or Z state"?

EXPRESSED BIAS OF SPEAKER – A CONTEXT FOR DISCUSSION

The above description may be considered by some overstated and cynical–but in my opinion it is realistic. While I consider planning and priority setting essential, I also consider there to be a mystique about planning which transcends reality. Sure there is a rational procedure or checklist of considerations for any decision, but it is not as refined as we would like to have it. Priority setting is at times (more than we would like to admit) an opportunistic, value-laden, power politics process. It is not always the rational choice of alternative strategies ordered on a continuum of most important to least important. At best, it is a choice among alternative strategies which themselves have been very often decided according to opportunism, personal values, and power politics. It is noted that opportunism, expression of values and power politics are not always negative. More on this later. What I am talking about is the human element and the realistic element in priority setting and the planning process.

The literature (see Bibliography) is rife with "models," "schemes," "theories," and "processes" concerning what planning and priority setting is and is not. We have had flow charts, diagrams, schematic drawings, tables or organization and the like, all indicating visually the planning process. The jargon includes "feedback" and "feedback loops," "interpretation," "interface," "multidisciplinary," "integrated services," "entropy," "advocacy," and "consumerism" to mention a few. All this combines to elevate planning to an "already-designed-infallible many-times-tested" social law. Not true! You know it and I know it.

The universal housewife makes decisions every Saturday at the supermarket without the use of theories, flow charts, or jargon:

> She makes priority choices based on money, family member's desires as to type of foods, her knowledge of what is easiest to cook, her tastes, her needs and that of the family for healthful foods, the needs of the house for detergents, cleaners, disinfectants..soap and other such nonedible supplies versus food, the availability and supply of material at her supermarket, their prices and specials, the choices of stores based on prices, distance, cleanliness and range of supplies. (One store has better meat–but slightly higher prices on non-foodstuffs.)

If you take this simple example and multiply it by $30 billion and hundreds of Health, Education, and Welfare agencies, and a plethora of competing crucial needs, we see that rational planning and priority setting is a difficult and crucial matter. However, in many cases, the amount of money one has to spend does not alter the subjective-human-value laden decision fraught with opportunism and power politics.

Now that the latter point has been made and a context for discussion established, let us look at priority setting in the planning process as we would like to practice it--as a rational choice objectively arrived at from among competing and complex, but well defined, needs.

We have all seen a checklist similar to the following which is intended to guide our planning and subsequent setting of priorities.

1. Establish sanctions for study of the problem.
2. Define the problem.
3. Determine the potential availability of knowledge.
4. Determine the necessary sources of knowledge.
5. Organize knowledge sources in a meaningful way.
6. Analyze problem.
7. Delineate major available tactical solutions.
8. Delineate major anticipated consequences of each of the proposed tactics.
9. Assess the sanctions available for each tactic.
10. Select the strategy.
11. Document and interpret.
12. Ratify strategy.
13. Designate the agent of the strategy.
14. Implement.
15. Assess the consequences of implementation.

The attached Appendix discusses in detail the points listed above. This "cookbook" is intended as a guide. No one problem even requires the use of all items. The object is to arrive at a "rational" analysis and action plan. A rational analysis means that all assumptions, presumptions, and facts are explicitly stated, that a logical chain of reasoning is exhibited, and relevant supporting data is cited. We must remember that an "assumption" is a proposition for which there is no evidence, but is believed to be true. A "presumption" is a proposition for which there is "more or less" evidence and believed to be true. A "fact" is a proposition for which there is enough evidence to make it probably true.

The following table "Analytical and Interactional Tasks by Phases of Problem-Solving" compresses, in many respects, the lengthy and detailed content of the Appendix.

ADDRESSING THE PROBLEM

"The identification of unmet needs" seems to be a simple enough task. However, when something appears too simple it is time to beware. The way in which a problem is formulated will strongly influence how it will be handled in the succeeding phases of problem solving. Gurin and Perlman use the following illustration.

> . . . the same set of facts about a population in "poor health" can be interpreted in quite diverse ways. One way is to put the emphasis on the lack of adequate income, which would account for bad housing and nutrition. Or the problem can be conceived of as the need for a new program that stresses health education. Or the problem can be formulated as non-use of medical services that are easily accessible to the population in question. In other words, the formulation of "the problem" to a large extent sets the direction for thinking about it and acting on it.

A case of shifting problem identification apropos to this conference is presented below.

378,TABLE 1

Analytical and Interactional Tasks by Phases of Problem-Solving*

	Analytical Tasks	Interactional Tasks
1. Defining the problem	In preliminary terms studying and describing the problematic aspects of a situation. Conceptualizing the system of relevant actors. Assessing what opportunities and limits are set by the organization employing the practitioner and by other actors.	Eliciting and receiving information, grievances, and preferences from those experiencing the problem and other sources.
2. Building structure	Determining the nature of the practitioner's relationship to various actors. Deciding on types of structures to be developed. Choosing people for roles as experts, communicators, influencers, and the like.	Establishing formal and informal communication lines. Recruiting people into the selected structures and roles and obtaining their commitments to address the problem.
3. Formulating policy	Analyzing past efforts to deal with the problem. Developing alternative goals and strategies, assessing their possible consequences and feasibility. Selecting one or more for recommendation to decision-makers.	Communicating alternative goals and strategies to selected actors. Promoting their expression of preferences and testing acceptance of various alternatives. Assisting decision-makers to choose.
4. Implementing plans	Specifying what tasks need to be performed to achieve agreed-upon goals, by whom, when, and with what resources and procedures.	Presenting requirements to decision-makers, overcoming resistances, and obtaining commitments to the program. Marshalling resources and putting procedures into operation.
5. Monitoring	Designing system for collecting information on operations. Analyzing feedback data and specifying adjustments needed and/or new problems that require planning and action.	Obtaining information from relevant actors based on their experience. Communicating findings and recommendations and preparing actors for new round of decisions to be made.

One of the important developments of the 1960's in the field of sectoral planning was the initiation of large-scale social welfare programs that called for a combination of Federal, State and local planning, decision-making, and financing. In particular, the states, following the provisions of Congressional legislation, obtained grants from Federal agencies and engaged in successive waves of planning in such sectors as mental health, rehabilitation, and mental retardation.

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*Perlman, Robert and Arnold Gurin. *Community Organization and Social Planning*, New York: John Wiley & Sons, Inc., 1972.

Planning in these categorical fields is typically an effort to mobilize resources and to achieve coordination of activities among all the services directly and indirectly involved in dealing with a specific area. It is, in other words, an attempt to be "comprehensive" within a sector by including all kinds of public and voluntary agencies and by involving citizen and consumer groups. This is illustrated in the following case, in which we trace the evolution of the national mental retardation program during the Kennedy Administration.

The case illustrates a number of points. It demonstrates the importance of the "definition of the problem" and it shows the parts played in shaping that definition by an aggressive consumers' association, by the President, the Congress, the Department of Health, Education, and Welfare, and a state department of mental health. The case portrays the impact that each actor's definition had on subsequent decisions.

The Case

From medieval times until well into the 19th Century, mental retardation was looked on as the work of the devil or as punishment for sinful behavior. Popular fears, later reinforced by theories of genetic determination, have produced a long history of ostracism and inhuman treatment of retarded persons, whether they were hidden in attics or kept out of sight in institutions. Following World War II there was a sharp increase in public interest and support for services to the retarded, generated mostly by local and state groups and a national association formed to advance the interests of the retarded.

These associations had grown out of local self-help efforts of parents to obtain better education and other services for their retarded children. Their small-scale demonstrations were buttressed by new knowledge of the multiple causes and forms of retardation. Most important, evidence was mounting that less-severely retarded children and adults were trainable and educable and could live at home—some independently—and many could be employed. The scattered activities of the parents' groups gave way in the 1950's to intense political activity aimed at getting changes in the policies of state agencies and in having legislatures appropriate more funds.

At issue in all this activity was the underlying question of the definition of retardation. What is it and what causes it? For a long time a medical or clinical frame of reference labeled all retardation as individual pathology, requiring diagnosis and treatment on an individualized basis (Holland(3)). An opposing view holds that mental retardation is more frequently a product of a faulty social system—that is, of bad health conditions, lack of prenatal and postnatal care, poor educational programs, and measuring and labeling devices that are themselves distorted by middle-class and professional biases. By 1960 research, some of it sponsored by the National Association for Retarded Children (Masland(4)), had called attention to the substantial economic, cultural, and social components in the causation of retardation.

Learning the growing concern, President Kennedy, made more sensitive by the fact that one of his sisters was retarded, used the medium of a nationwide TV address to appoint a panel in 1961 to make a study and recommendations. In his mandate to the panel, Kennedy tried to set the terms and the tone for what was to follow. He defined retardation not as a disease but "as a symptom of a disease, of an injury, of some obscure failure of development, even of inadequate opportunity to learn." He called it a national problem requiring a national solution and he instructed the panel to explore "the possibilities and pathways to prevent and cure mental retardation," to appraise the adequacy of existing programs, to identify gaps, and to recommend the programs that were needed (President's Statement(9)).

The panel's 200-page report emphasized research and prevention and made some 90 recommendations covering clinical and social services, methods and facilities for care, clarification of the legal rights of the retarded, the need for increased manpower, and public education on retardation (President's Panel(8)). The panel urged that the new program thrust should be (1) comprehensive, that is, including day dare, recreation, residential services, and education and vocational opportunities; (2) community centered, operating close to where the retarded live; and (3) coordinated so as to assure a sufficient array or continuum of services to meet different types of needs. The fourth policy recommendation departed from the President's perception of the national scope of the problem and placed the "principal responsibility" for financing and improving services on the states and local communities, although it suggested Federal aid to the states for planning purposes.

Using the panel's findings and recommendations, the President asked Congress to provide larger appropriations for certain existing programs and for special project grants to be awarded to state agencies "presenting acceptable proposals for this broad interdisciplinary planning activity" (President's Message[7]). The President stressed, as the panel had, the strong link between retardation and socioeconomic deprivation. While some retardation could be traced to biomedical factors, he said, the great bulk of cases for which the cause is not clearly known shows a remarkable correlation between the incidence of mental retardation and the living conditions of families deprived of the basic necessities of life.

It is important to note the shift that was taking place in the approach to the problem. When Congress enacted legislation in 1963, it provided Federal matching funds for perinatal medical care for indigent mothers, support for comprehensive planning by the states, and money for constructing new facilities. This was, in effect, a retreat from the view of retardation as largely a social-structural problem and was a reversion to the individual pathology-service approach (Holland, p. 27(3)). Connery reports that in the Congressional hearings preceding passage of the legislation, the American Medical Association mounted a strong attack on any proposals to change the definition of the problem and opposed the emphasis on the social aspects of causation. (Connery(2)).

"Major national social programs were avoided in favor of state responsibility. And at the state level, Connery continues, the medical profession continued its opposition to government involvement in programs for the retarded, and then it insisted that any services that were implemented should be attached under the control of existing hospitals and medical programs.... Popular American ideology of an open social structure and individual responsibility precluded many from even hearing the idea that the social system would upset the current social allocation of statuses and resources."(Holland, pp. 33-34(3)).

The passage of legislation, however, only indicates the will and intent of the legislators; responsibility then passes to the administrator to implement their intent through his regulations. In this case it was the Department of Health, Education, and Welfare, which issued its guidelines for planning by the States seven months after the new laws had been enacted. (HEW(6)) The publication explores the difficulties of achieving interagency coordination and suggests approaching this through improved communication, closer cooperation and the use of authority. The guidelines list the areas to which attention must be given (for example, prevention, clinical services, records and reporting, and financing) and then suggest these steps for building a structure and taking the first analytical steps in the planning process:

1. Establishing an "executive-level policy group, composed of top personnel" in the agencies concerned with retardation.

2. Setting up a broadly representative advisory committee of State and local public and voluntary agency personnel.

3. Having the planning staff evaluate the retardation situation, making rough estimates of existing resources, needs, and a determination of that additional services, personnel, facilities and other resources are required. This planning should dovetail with the planning of physical facilities and specific goals should be set for services.

After these steps, "the plan can then be developed" to include provision for coordinating mechanisms, case-finding procedures, service components, evaluation, regional organization, the stimulation of greater public awareness, and the drafting of necessary legislation.

Within three months after the appearance of these guidelines, a planning project was activated in Massachusetts, where the State Department of Mental Health contracted with a voluntary health organization to do the planning (Massachusetts(5)). The structure followed the Federal guidelines and consisted of a top-level policy board of the heads of relevant state agencies plus the chairmen of nine task forces set up to deal with various aspects of the problem. During the 2½ years before it reported to the Governor, the planning project conducted inventories of facilities and services, held hearings around the state "to feed data into the decision-making machinery and to increase local identification with, and commitment to, comprehensive planning," and designed a special study of the characteristics of potentially employable retardates.

The planning board recommended to the Governor a system of decentralized programs in 37 areas within the state and set forth its own guidelines for the specific services to be developed locally. The existing institutions were to shift to an emphasis on social development of retardates and to an "individual and small group approach and meaningful links with the community." Support of new programs of special education and of preventive work was recommended, and the board urged that, in addition to the $50 million then being spent each year on retardation, $13.7 million would be needed annually by 1968 and $45 million would be needed by 1976.

But the board felt that the major problem was one of coordination. It found itself may be handicapping some individuals' chances for growth and development. At this point the popular ideology and the medical perspective on retardation meshed closely to produce strong opposition to any changes which that 50 of its specific recommendations reflected the "need for an interdepartmental planning agency." The political problem could be summed up simply: which of the seven state agencies serving the retarded would be designated the coordinator? Moreover, how could this be resolved with all these departments heavily represented on the planning board?

The solution was to create a new agency, an Office of Retardation, which would be responsible directly to the Governor. The new agency, presumably a neutral among the large agencies, would "develop, and keep current, a state plan to aid retarded persons; establish standards for services; provide liaison with the federal government; and assist all departments and other agencies and organizations to improve their programs and services for the retarded" (Massachusetts, p. 3(5)).

Without tracing the process beyond the preparation of these recommendations, this account has indicated something of the nature of planned change. In the 4½ years covered by these events there were some changes in the distribution of resources, power, and functions. This was due in part to the concerting of energy by the parents of retarded children, in part to growing public concern, and in part to Presidential leadership. But the thrust to redefine retardation as primarily a failure of the social system was blunted, and the massive changes that some wanted were denied. This was the result of the opposition of certain political leaders and of some professionals and bureaucrats who were protecting their domains, as well as being the reflection of old but persistent public attitudes toward the retarded.

Running throughout this case illustration has been another theme: the difficulty or at least the undesirability of isolating mental retardation as a social problem and the mentally retarded as people from the rest of society. This fundamental limitation in sectoral planning has given rise over the years to different kinds of planning bodies that strive to cut across service fields and problem areas such as the welfare council.

REDUCING HUMAN ERROR AND IDENTIFYING UNMET NEEDS

One of the ways to reduce emotional laden value decisions in any area is to do a good piece of research. This should be conducted by someone not integrally tied into the "movement" or "cause" espoused by the group asking for the research. This author nearly 2 years ago was asked to conduct a survey of existing facilities and services for epileptics in the State of Texas (Arangio(1)). (By way of a note I am a Board Member now of Dallas Epilepsy Association. In addition, I am on the Professional Advisory Board of the Tarrant County Cerebral Palsy Association. Furthermore, I was, several years ago, Assistant Director of Louisiana State University Special Education Department doing diagnosis and planning for children with varying exceptionalities.)

When you have research to conduct a good source of manpower can be found at your nearest university. Professors are always hungry and/or have students in need of exciting and imaginative projects.

While the survey I conducted confirmed suspicions of the state of the services and facilities (lacking) in Texas, it also established baseline information for further planning through the listing of 16 gaps. All of us in the health planning field are often forced to plead our case with emotionalism. How good it is to be able to back requests for funding and volunteers with hard raw data.

Problems in all surveys arise when the time comes for the interpretation of the data:

1. Suppose the information doesn't show the need?
2. Did we pay enough attention to the professional respondent and how he or she defines the need?
3. Did we take into account the consumer?
4. Was the advocate agency involved sufficiently in the statement of need?
5. Even if we asked everybody we conceptualized as important to the definition of need and the assignment of priorities, WHAT INFLUENCED THEM TO ANSWER THE WAY THEY DID?
    - A. Were there hidden agendas?
    - B. Are they speaking from their heart or mind, or both?
    - C. Are there others who would categorically oppose these statements?
6. How generalizable is the data to the population of respondents as a whole?

Now some might ask, "Who will ask these questions?" The answer? Almost anyone—but especially those who are competing with you for programs and service money. Perhaps, if we were to admit it, the reason for doing surveys very often is to stifle such questions.

We must remind ourselves that different people have different perspectives as to needs. This perception is influenced by allegiance to a competing cause, personal values, and assessment of needs similarly researched as your own survey.

Let us get down to nitty-gritty points. Once again, allow me to point out my own bias and then you can judge from your own value position what I have to say.

It is my opinion that the existence of voluntary health associations is a commentary on the partial failure of our health system to fulfill its responsibilities. If one were to continue this argument, it becomes apparent that the growth of these agencies was an expression of gaps in service or in some cases, unidentifiable needs. The three disabilities represented here, retardation, epilepsy and cerebral palsy and their associations are responses to gaps in health delivery. It is also apparent that THEY ARE COMPETING ENTITIES. Why this sense of competition among these eleemosynary groups—because their needs are so great and the wherewithal and money so little. We must compete as General Dynamics, Bendix, and others compete for contracts. However, these industries seem to have other places to go when they lose the money and the contract.

In this context, there appears to be no end to the expression of need for priorities. Who will set them? Some who add up the tally sheets at the end of the fiscal year and are at the short end of grants and the like feel the priorities have already been set.

Let us read the first paragraph of the handout explaining the Developmental Disabilities Services and Facilities Construction Act P.L. 91-517.

> The Act defines developmental disability to mean a disability attributable to mental retardation, cerebral palsy, epilepsy, or other neurological handicapping condition of an individual found to be closely related to mental retardation or to require treatment similar to that required by mentally retarded individuals, and
>
> the disability originates before such individual attains age 18
>
> and has continued, or can be expected to continue, indefinitely
>
> and constitutes a substantial handicap of such individuals.

How does one interpret this paragraph?

1. It covers only those individuals who are functionally retarded, or retarded due to epilepsy and/or cerebral palsy.
2. It covers epileptics and cerebral palsied as secondary diagnosis to retardation.
3. It covers the non-retarded cerebral palsied and epileptic.
4. It covers "developmentally disabled" individuals regardless of diagnosis as long as it is a neurologically handicapping conditions.

How would you answer this question? Think for a moment and express your choice. (Ask audience to raise hands in response to 1-4.) (If significant #'s for 1, 2, and 3 and not 4—continue with discussion of competition stressing the spirit of the Legislation.)

Were our decisions objective or subjective? Were they in accordance to an allegiance to a cause, or different? Can you believe there is ever a time when you will have enough to serve your category of the developmentally disabled so as to defer to the other groups?

All of you have data to support your requests for grant money but who is to get the greatest share? How is this share to be determined? What criteria for priority setting will be followed?

Certainly there can be cooperative ventures designed across disability lines but who will run them? You notice at this point that all I have done for the past several minutes is to ask question, not answer them.

However, there are more questions to ask and discuss in a few minutes when we throw this open to the panel and the audience.

Are the priorities for this legislation determined at the top and filtered down, or is there a constant realignment of priorities based on information flowing upward as well (feedback)—that word again?

Under the legislation—DDSA—epilepsy and cerebral palsy have gained heretofore non-existent funding for programs, services, and the like. What effect on the market place does the addition of categorical disorders have? Can local agencies express the true state of the existence, nature, and treatment of the developmental disabilities they advocate for?

What right things to avoid the many pitfalls expressed in the preceding question did the administering agency for this legislation do?

1. Certainly, there has been a continuing dialogue vis-a-vis Washington and States.
2. State plans had to be designed and submitted. The process involved at each state level was to aid in the cooperative nature of the project.
3. The formation of state councils insures to a certain degree that administrators, professionals, and consumers would be represented.
4. The mini-grant year focused on planning, survey of needs, and program development. In fact, the change in the percentage of funding from year to year, from planning to service, was a wise choice of guideline.

There are of course, many other positions. However, those above pertain to our topic. The process was prescribed by the above structural constraints. However, the big three-values, opportunism and power politics–played a larger part than was designed. YOU CANNOT LEGISLATE NON-COMPETITION. YOU CANNOT LEGISLATE COOPERATIVE VENTURES.

The agency which is "on the line" (and they don't let you forget they are) is vociferous in its demands, but lacks power; little solace to the agency which can point to A, B, or C percent of funding directed toward their cause (but to an agency in another state).

Agencies complain about lacking grants and manpower expertise. Agencies complain about the lack of money to fund staff. After all, who is to run a program–volunteers? But where is the agency getting its information? What goals and priorities have they set up? Were funding possibilities on the last page of a well conceptualized program or on the front page of a poorly conceptualized one?

How many of us have dramatically shifted priorities when the word came that a "new and innovative child advocacy program will be funded"? All this shifting of priorities is usually in the name of "flexibility."

PRIORITY SETTING OR MUDDLING THROUGH?

What is one to do about the harsh realities of the muddle of needs, counter-needs, competing priorities, a plethora of opportunistic planning and priority setting?

1. Acknowledge that competition exists.
2. Acknowledge your intense desire to fight for your cause against other causes.
3. Be honest.
4. Find common meeting ground with your adversaries.
5. Find program policies, program systems that you can share.
    (a) Not everyone needs its own transportation system.
    (b) Not everyone needs its own neurological consultant team.
    (c) Not all might need their own specialized social service staff.
    (d) Not all need their own team of rehabilitation counselors.

Pool these resources, continue to fight for your rights, refuse to be co-opted and find that you can live together.

6. Write cooperative grants for the DEVELOPMENTALLY DISABLED.
7. Work together to insure that the fiscal tally sheet short changes no one at any particular time.
8. Conduct training seminars for each other and other professionals—share information.
9. Acknowledge that some agencies are newcomers—help them get established—don't ignore them and let them waste their time and energy.
10. Remember, we are not helping our consumers by bickering.

SUMMARY

There is a concept of rational planning and priority setting. It is an attempt to structure and objectify human thinking and emotion laden values. It (the priority-planning theory) tries to keep us "honest." However, the "rationality" of the priorities and plans lies largely in opportunistic decision making, in values, and in power-politics decisions of the human beings who are designing and exercising the plans. Many forces shape the plans and priorities; the determination of unmet needs (how and why), the perceptions by many actions or these needs, the weighing of data, agency demands, vis-a-vis local, state, or regional priorities, and shifting circumstances in many structures.

There are many ways to resolve the differences—among the most important are the acknowledgement of a strong interest to advocate for a cause and an effort to work cooperative ventures.

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Appendix

MAJOR STEPS IN A PLANNING MODEL

I. **Problem Definition**:

In general determines the present perceptions of the problem *as presented* in terms of its conflict with a prevailing social value.

II. **Problem Assessment**:

In general
a. Refines the problem to measurable and understandable proportions.
b. Is not limited in analysis by prior definitions, solutions, conceptions, etc. Nothing is taken for granted.
c. Understanding, rather than solutions, is the primary object in this stage.
d. Assumes that problems, their causes, and consequences cannot be unitary.

III. **Action Strategies for Coping With Problems**:

Determination of action plans assumes that a rational scheme is required. It assumes that:
a. A number of potential strategies are potentially available for any one social goal.
b. Strategy choices are made on the basis of predicted consequences, available resources, values held, and timing considerations.

A. Problem Definition

1. How is the problem stated?
2. By whom is it stated? Does he wish action on the problem?
3. Who else acknowledges the problem? Do they wish action on the problem?
4. Are there variations in how the problem is stated?
    a. Are some statements contradictory?
    b. Are some statements contrary?
5. Are there stated solutions to the problem? By whom?
6. Who denies (it is said) the existence of the problem?
7. Why was the problem presented to you, rather than others?
8. Was the problem previously presented to others? If so, what was their reaction to it?
9. Who suffers most (it is said) from the existence of the problem?
10. Who benefits most (it is said) from the existence of the problem?
11. What conflicts are there in the social values held (by you, your sponsor, your profession, the sufferers, the affected social institutions, others involved in the problem), as implicitly imbedded in the statement of the problem?
12. What are the conflicts in social values held (by the above) and the various "solutions" initially proposed?

13. Do you have the required sanction to proceed with the analysis? With the design of action steps? With carrying out desirable action steps? Where and how can this be obtained? What alliances are necessary at this point to enhance these sanctions? Which will you need to plan for later on?
14. Is it clear that someone will be mandated to carry out the action plan?

B. Assessment of the Problem

1. Knowledge Sources:

- a. Where is the problem localized? (Geographical area, population group, organizational grouping, etc.) (Cite data.)
- b. How long has the problem been known to be in existence? To whom has this been known? Are there variations in how long it has been known to different people or organizations? (Cite data.)
- c. How have the perceptions and the characteristics of the problem changed over time? (Cite data.)
- d. Have the mass media, or other public information media, given attention to the problem? Recently? How have they interpreted the problem?
- e. Which individuals, occupations, or organizations claim to have expert knowledge about the problem, or are potential sources of such knowledge?
- f. Which of the above are potentially available to the community worker as expert consultants? What sanction and time factors have to be considered to assure their availability?

2. Organizations Related to the Problem:

- a. What organizations (local, regional, or national) are:
  - i. primarily mandated to prevent and/or alleviate the problem?
  - ii. mandated to resolve portions, or related aspects of the problem?
- b. What organizations are affected by the problem? How? Do they appear to be conscious of the problem? How?
- c. Which of the various affected or mandated organizations are reputed to be "powerful"? Which individuals on Board and Staff are said to hold this power?
- d. Describe the programs and the services of these organizations in terms of what they have done in the past and are doing now in regards to the problem. How do they measure up on the following dimensions?
  - i. legal basis for dealing with problem
  - ii. accessibility
  - iii. relevancy
  - iv. need
  - v. demand
    - (i) effective demand?
    - (ii) ineffective demand?
    - (iii) need–demand discrepancy?
  - vi. personnel
    - (i) quality?
    - (ii) quantity?
    - (iii) personnel freedoms?

        (iv) personnel restrictions?
    vii. tools and resources
    viii. facilities
    ix. program content
        (i) types of programs
        (ii) quality
        (iii) quantity
        (iv) methods and techniques used (e.g., casework, group work, psychotherapy, etc.)
    x. organizational and administrative standards

e. How adequate have been (and are now) the methods and techniques used to cope with the problem? (Cite data.)

f. Are any prominent individuals said to be involved with the problem? As promoters of change? As promoters of a "status quo"? What are their reputed posture, activities in relation to the problem and possible explanations for these?

g. What obstacles have these organizations and individuals met with in the past, and now, which make their efforts inadequate (policies, personnel, facilities, finances, etc.)?

h. What cooperative and/or conflicting actions have taken place between organizations (or primary actors), locally, regionally, and nationally in regards to this problem? Why have they been in conflict? Why have they cooperated?

i. What is the position of the community practitioner in the agency which employs him? What is his organization mandated to do about the problem? What constraints are placed on his activities by the organization in regards to this problem? What are the negative and the positive aspects of these constraints?

3. *Those Affected by the Problem (Target Population):*

a. What are the life circumstances of the people affected by the problem? (Cite data.)
    i. culture and life styles
    ii. race–ethnic characteristics
    iii. religion
    iv. income characteristics
    v. shape and trends of movement and growth
    vi. households and their formations
    vii. density
    viii. housing and neighborhood characteristics
    ix. health and disability patterns
    x. education
    xi. occupational patterns
    xii. age
    xiii. etc.

b. How widespread is the problem? How is it affected by the above variables? (Cite data.)

c. What is the predicted future growth of the problem? How is it affected by the above variables? (Cite data.)

d. What are the consequences of the problem (on the organization(s), on their personnel, on their finances, management, on their clientele, on the bearers of the problem, on the community, the economic system, the political system, etc.)?

e. What is known about the attitude towards the problem by?
    i. *those who suffer most* from the problem? Do they recognize it as a problem? Do they appear to want it to change? What proposed solutions have they promoted?
    ii. *those who benefit most* from the problem? Do they recognize it as a problem? Is there any evidence of a willingness to have it changed? What changes are they most willing to adopt?
    iii. *those who most wish to change it?* Why do they wish to change it? What will they gain out of such action? What proposed solutions have they promoted? What amendments to such solutions might they adopt? How essential are they to an action scheme?

4. *What Are the Potential Resources for Dealing With the Problem?*
    a. State of the economy
    b. Industrial development and investment phenomena
    c. Manpower utilization and availability patterns
    d. Public expenditure patterns
    e. Private consumption patterns
    f. Land use patterns
    g. Policies, laws and regulations
    h. Political climate
    i. Etc.

5. *What Are Existing Social Standards Related to the Problem?*
    e.g.,
    a. Health and welfare standards
    b. Who is mandated to police standards?
    c. What organizations are available to enhance standards?

6. *Explanations for the Problem:*
    a. What general explanations are available to account for the existence of the problem? (Sociological? Psychological? Political? Economic? Other? (Cite data–books, articles, studies, etc.)
    b. Which explanations did *you* adopt? Why this rather than another? Because it was the most efficient explanation? Or because of values held? Or because it offered grounds for employing available skills and resources?

C. ***Goal(s) and Method(s)***

The requirement is to set goals and determine the methods to achieve these in order to resolve, reduce or stabilize the problem.

1. *Goal Choices:*
    a. What knowledge is available about the efficacy and requirements of
        i. prevention (primary intervention between "preconditions" and "causes" of the problem)
        ii. treatment (secondary intervention between "causes" and "effects" of the problem)
        iii. rehabilitation (tertiary intervention between "effects" and "consequences" of the problem)

b. To what extent is your choice of goals determined by:
  i. your commitment to resolve the social problem?
  ii. your personal, or organizational requirement to be "involved," to gain satisfactions, or to gain recognition?
  iii. are these in conflict?

c. Bearing all of the preceding in mind, what *general* goals have you adopted?
  i. resolution of the problem?
  ii. reduction of the problem?
  iii. stabilization of the problem? (To stabilize means to prevent further growth or development of the problem.)

d. i. What *long range* and *short range* goals will you adopt in regard to the problem (bearing in mind all of the above)?
  ii. How does the explanation adopted for the existence of the problem condition, or influence, the choice of long and short range goals?
  iii. Do the short range goals advance or retard the achievement of the desirable long range goals?

e. Is the social goal oriented towards
  i. corrective-adaptive adjustments of the problem?
  ii. institutionalized-generalized resolutions of the problem?

2. *Method Choices:*

a. Which organization(s) or individual(s) have the greatest potential for obtaining
  i. the necessary sanctions
  ii. the necessary resources (time, money, personnel, facilities, access to the knowledge sources, interest, etc.)

in order to resolve, reduce, or stabilize the problem?

b. Are there established, recognized, channels for handling such problems? Are there strong arguments for not utilizing established channels? What are the likely consequences of not using such channels (e.g., attitude of people who work with or within such channels)?

c. Bearing all of the above in mind, will you elect to:
  i. primarily use your own resources
    (i) for short range goals?
    (ii) for long range goals?
  ii. use your organization's resources
    (i) for short range goals?
    (ii) for long range goals?
  iii. use one or more of the individuals and/or organizations identified in "a" or "b" above
    (i) for short range goals?
    (ii) for long range goals?

d. i. What methods do you plan to utilize to achieve the short-range goals?
    (i) concensus approach
    (ii) conflict approach
  ii. What are your targets of intervention?
    (i) the client system
    (ii) the service system

iii. What are your vehicles of intervention?
  (i) the client system
  (ii) the service system

e. i. Enumerate the various specific steps, in sequence, which you would anticipate taking, including a tentative timetable. Be as specific as possible. Cite major alternate routes to be taken if planned events do not follow your prescription.

ii. Determine for each step:
  (i) the likely consequences:
    (a) social
    (b) psychological
    (c) economic
    (d) political
    (e) organizational
    (f) etc.
  (ii) acceptability to:
    (a) the action group
    (b) the target group
  (iii) technical feasibility and requirements (e.g. documentation)
  (iv) required sanctions
  (v) availability of resources required
  (vi) its rational progression from prior steps

iii. Does your scheme in general answer the following questions?
  (i) *policy decisions required*
    (a) by whom?
    (b) about what?
  (ii) *resources needed and their sources*
    (a) financial
    (b) personnel
    (c) facilities
    (d) equipment
    (e) other
  (iii) *specific obstacles to be overcome*
  (iv) *planning issues*
    (a) centralization versus decentralization
    (b) specialization versus generalization
      a) of services
      b) of personnel
      c) of facilities
    (c) tax support versus voluntary support versus commercial auspices
    (d) comprehensiveness
    (e) continuity of care
    (f) accountability
  (v) *available support*
  (vi) *planning sequence*

iv. Does it also anticipate the consequences of implementation, differentiating between *short term consequences* and *long term consequences* on each of the applicable following items?
  (i) *on quantity of services*
    (a) quantity of production
    (b) quantity of demand
    (c) quantity of need

- (ii) *on quality of services*
  - (a) same quality of services
  - (b) different quality of services
  - (c) quality of demand
- (iii) *on resources needed*
  - (a) financial
    - a) costs of services
    - b) income for and/or from services
  - (b) personnel
  - (c) facilities
  - (d) equipment
  - (e) other
- (iv) *on types of services rendered*
  - (a) same requirements as initially
  - (b) different requirements over time
- (v) *on related social systems*
  - (a) related programs or social movements
  - (b) related financing systems
  - (c) related populations
  - (d) other

v. Were the methods, and the specific steps chosen because of values held? because of feasibility? (knowledge and skill of worker, resources of his or other organizations, readiness of organization or others affected by the problem to cooperate and participate? Resistance by individuals, groups, organizations? Other?)

f. Are the methods and specific steps chosen oriented towards
- i. corrective-adaptive adjustments in the problem?
- ii. institutionalized-generalized resolutions of the problem?

(See e. above)

g. Will the potential gains of the successfully applied strategies outweigh the potential costs to the respective client systems?

D. *Documentation and Interpretation*

1. documentation
   - a. an organizational requirement?
   - b. a requirement of the action strategy?
   - c. if for both, are the documentation requirements the same or different?
2. Who are the potential audiences or readers? Do they have special qualities and/or requirements which dictate the type or style of the presentation?
3. Is the purpose best served by
   - a. a technical or scholarly presentation?
   - b. a simplistic, "streamlined" presentation?
   - c. combinations of both:
     - i. interwoven technical information and recommendations
     - ii. findings and recommendations separated from technical analyses
4. Is the requirement for:
   - a. historical material?
   - b. descriptive material?

  c. analytical material?
  d. conclusions and recommendations?
  e. delineation of the process used in making the study?
  f. specification of the sanctions behind the study?
  g. recognition for:
    i. efforts expended in the study, and/or
    ii. efforts and attitudes of the potential readers in the general problem area?

5. Is there a clear separation between facts and findings, and the conclusions (or interpretations) made?
6. Has the documentation been purged of all superfluous materials which are unnecessarily detailed, repetitive, or potentially offensive or threatening to those whose support is essential?
7. What type of organization of material is required to assure that
   a. it will be read
   b. the most critical points will get assured attention
   (also type and color of paper, printing, illustrations, etc.)
8. Who will require copies for administrative, action, or courtesy purposes?
9. What type of delivery will assure the desired effect?
   a. verbal presentations
   b. general mailings
   c. personal distribution
   d. distribution through channels
   e. use of other visual aids (e.g., radio, TV, projectors, etc.)
   f. distribution followed by formal or informal discussion.
10. Does the setting for the interpretation make a difference?
11. Who are to be the primary interpreters and discussants of the document and its message? Can one person do this, or will it require different people to specialize in different aspects of the report? How will this vary according to the audience? Are there prestige factors involved? Are there communication factors involved? Are there political implications?
12. If the document is to result in action, does strategy dictate that it specify who is to be held accountable for the necessary action(s)? Or is strategy based on the assumption that the audience (e.g. readers) will insist in retaining this prerogative? If the latter, are preparations necessary to alert representatives of that audience before, during, or after the initial presentation to this expectation?

E. *Ratification and Action*

1. Is ratification of the proposed action necessary from more than one individual or group? Are these sources of sanction especially responsive to some of the available interpreters of the message? Is sequencing in ratification from more than one source of importance in building power?
2. Which available individuals who are potentially sympathetic have the greatest potential for obtaining the desired ratification? Will they require help in achieving this?
3. What are the least harmful available compromises of the general proposal which will still enable the primary goal(s) to be approached? How will they change available strategies?
4. Has a clear specification been made by the ratifying body (or bodies) of who will take primary responsibility for the necessary action? Has this "see-to-it" agent been advised and

consented? Does he (or the organization) have the necessary abilities?

5. Have the necessary time and resources been provided for the action phase? Are additional arrangements necessary?
6. Does the "see-to-it" agent have the necessary information developed in the study phase? Does he know about the available sanctions and resources? Is it clear to whom he is accountable?
7. Does the action system know about the "see-to-it" agent? Does it view him as acceptable and appropriate? Does it define itself as appropriate to the mission? Does it have representation and participation requirements of its own?
8. What other ties are there within the action system which bind it together? Which are the strongest ties? Which are potential internal points of friction or other difficulties?
9. What are possible approaches or techniques for the "see-to-it" agent to assure continued group cohesion and goal focus on the part of the action system?

F. Assessment of Implementation Consequences

1. Are there "reporting back" requirements to the sponsoring or sanctioning bodies as developments take place? Is it prepared to reassign responsibility if the desired action does not take place?
2. Are there built-in assessment schemes on
   a. progress made?
   b. continued utility of the strategy system?
   c. utilization of resources?
   d. continuation of necessary supports and endorsements?
3. What is to be learned from this experience which will
   a. avoid future repetition of difficulties?
   b. enhance future analytic or action assignments?
4. Has the experience opened opportunities for new problem solving approaches or for further work towards the more general long-range goals?

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Planning at the Community Level

Leopold D. Lippman

Planning is a means to an end: the provision of services and facilities which will enable developmentally disabled persons to grow to their full potential as participating members of society. To this end, planning is more than useful; it is essential.

With planning, the effective utilization of all available resources can bring each individual to the highest level of functioning that his disability permits. Without planning, a state may have a variety of unrelated and uncoordinated programs, costing a great deal and accomplishing little.

Participants in Developmental Disability Councils are already committed to planning, at the state level. To make the most appropriate use of available funds and other resources, state councils should recognize that the effective provision of services requires also *planning at the community level.*

In California, for example, the State Developmental Disabilities Planning and Advisory Council recently heard from its Master Plan Committee that, at the critical beginning phase, putting resources into that which will make the system work is even more important than funding service delivery components.

It is at the community level that ideas and good intentions become reality, because it is there–at the community level–that the individual seeks and receives services. (The word "community" has different meanings, depending on the age of the individual, the degree of disability and the nature of the service. For example, for some severe conditions, where specialized residential services may be required, and in a thinly-populated state, there may be only one facility suitable to the circumstances. Even in this extreme case, the facility should be envisioned as part of the pattern of services available to each individual who needs it. For most individuals, that need will be expressed at the outset in the communities where they are. The development and provision of such a statewide service, then, should grow out of *planning at the community level.*)

GOALS OF COMMUNITY PLANNING

As a realistic matter, most communities in the United States now have *some* services, no matter how inappropriate, inadequate or substandard they may be. The problem of the moment, in implementing the Developmental Disabilities Services and Facilities Construction Act, is to determine how the available resources may be used to extend, improve or augment the existing services. This cannot be done without determining the present and anticipated need, making an inventory and assessment of existing services, and setting priorities within the list of services to be improved or provided. Such is the task of planning.

Planning takes account of all the needs: known, estimated and anticipated. For the developmentally disabled, it includes the full age range (starting before birth, for effective prevention); it includes all the disabling conditions as they occur, singly and in combination, from mild to totally incapacitating. It goes beyond the disabled individual to consider his family and others in his social environment.

To be effective, planning should face the need for a continuum of services. This means (a) the full range of services, with (b) mechanisms to interlink them.

The range of appropriate services will depend on the community (that is the point of the planning), but the areas of need undoubtedly include: prevention, casefinding and diagnosis, family counseling, health care, supportive services in the home, preschool care, respite for parents, special education, vocational training, employment, housing, recreation, financial and legal assistance, transportation and architectural accessibility. It will not be possible to establish all such services at once, but the full scope of the ideal program should be clear from the beginning. Having conceived the desirable pattern of services for the community, the planning body can then develop a step-phase plan, with a time schedule, both subject to modification in the light of future developments.

National organizations devoted to specific disabilities have developed (and their state and local affiliates have access to) descriptions of comprehensive patterns of service. (Messner's chapter in Cruickshank's[3] book *Cerebral Palsy* offers a detailed and useful outline.) A particular community may not be able to implement the full list of recommendations, but it should be aware of the full scope of the problem and proposed solutions, as perceived by the knowledgeable specialists.

Comprehensiveness and continuity, though related, are two different matters. It is not enough to provide every kind of service a community may need, utopian though that may sound. It is necessary to interrelate the various services – most especially for those who are dependent because of a physical, mental or other handicap. Thus, for example: diagnosis should be coupled with family counseling and with prompt and effective referral to needed services; special education should be designed to, and should in fact, lead to prevocational evaluation and vocational training; residential care should be accompanied by provision for leisure-time activities; and the use of virtually every service depends on the availability of suitable transportation. It would seem essential that a community provide, in some manner, an information and referral service which meets the needs of every disabled individual and his family, at every stage of his life. Beyond this, every provider of service in a community should be aware of the other resources, and should know when and how to help the individual make his way to the alternative or supplementary service he may need.

CONSIDERATIONS IN COMMUNITY PLANNING

Effective planning begins with a realistic inventory of existing resources and needs. (There is a brief but helpful chapter on "Surveying the Need" in Allan's *Rehabilitation.*[2]) Planning at the community level, however, as at the state level, cannot be content with an assessment of present resources and present needs. To be effective, it must confront the likelihood of change. Wherever in the world you live, and whatever the scope of your responsibility, be confident there will be change. The only questions are what kind, how much and when? Fortunately, there are clues to the answers. Here are some probabilities for community-level (and state) planners to take into account:

A. The population of people needing service will change. Some changes are unique to the community; others will be characteristic of our whole society.

1. Changes in total numbers and in age distribution. Generally, the population is rising, but in a particular area it may be stable or falling, depending on the local economy and numerous other factors. One must examine present and projected birth rates, death rates and migration into and out of the area. The number of women of child-bearing age, changing attitudes toward optimum size of family, availability of contraceptives and legalization of abortion, all may have effects on the local birth rate. At the other end of the age scale, the rising life expectancy will mean additional disabled adults for whom to plan and provide services. A less obvious factor is that as a community establishes services, people come there to benefit; this was more true when services were comparatively rare and of uneven quality.

2. Changes in types and degrees of disability. As a result of scientific discoveries, some disabling conditions are now fully amenable to prevention. On the other hand, the declining infant mortality may mean the survival of more damaged children. War-related injuries, automobile accidents and other traumatic effects of our complex civilization are adding to the disabled population. Related is the fact that more severe disabilities are no longer always fatal.

3. Rising prevalence. As antibiotics, organ transplants and other medical innovations extend life, more people will live longer with disabling conditions. The problems are not only of a rising client population, but of one which is changing, by virtue of the age shifts. Elderly people, whether they have been developmentally disabled all their lives or have become handicapped relatively recently, present different problems from children and young adults.

4. Declining incidence. Genetic counseling, amniocentesis and legalized abortion will reduce the incidence of many disabling conditions. Thus, the emphasis of needs will shift.

B. Patterns of service will change. There are sociological, legal and other forces at work in our nation today which will influence the programs that society expects or allows.

1. The traditional and long-time exclusive solution to the problem of mental retardation was the state institution. Currently, state residential facilities throughout the United States are under severe criticism, some of it topical and

some of it basic. Changes have begun, and there will be more. New York and some other states have developed small group living arrangements at the community level; and what was originated for the mentally retarded is now being adapted for the recovering and restored mentally ill. The State of Washington has an extensive program of group homes, which are housing increasing numbers of former residents of the state schools for the retarded. California has evolved a funding pattern whereby the state and the counties share on the same ratio (90-10) for the mentally disordered, whether they are served locally or in a state hospital. Some of the new directions were pointed out in a challenging book published in 1969 by the President's Committee on Mental Retardation, *Changing Patterns in Residential Services for the Mentally Retarded,* edited by Kugel and Wolfensberger.[11]

2. A series of lawsuits and court decisions, begun in 1971 and continuing to the present, is introducing a new element in the enforcement of adequate services. In Pennsylvania, Alabama, Massachusetts, Utah, the District of Columbia and elsewhere around the United States, there have been class actions in behalf of mentally retarded and other persons, and Federal judges have accepted jurisdiction in cases asserting the "right to education" or "right to treatment." The Office of Mental Retardation Coordination publishes a frequently updated report on the status of current court cases; entitled *Mental Retardation and the Law,* it is prepared by Paul Friedman,[5] of the Center for Law and Social Policy. As successive cases come before the courts, it is clear that the decisions have implications for education, treatment, and habilitation of persons with other handicaps as well as the mentally retarded. The judicial assertions have been augmented, in recent months, by the opinions of attorneys general in several states; also a new wave of legislative proposals is moving through state and Congressional hoppers.

3. Attitudes may change. Thus far, this is more a hope than a fact. Two books published within the past year– *Attitudes Toward the Handicapped: A Comparison Between Europe and the United States* by Lippman,[13] and Viscardi's[18] *But Not on Our Block*–focus on the problem of the social milieu in which programs develop. Change has begun, however, in some places. The regional center program in Connecticut and the advocacy program in Nebraska have incipiently brought about attitudinal changes.

C. As some needs are met, others become more salient. For example:

1. When there were inadequate diagnostic facilities for young children, the specific nature of developmental disabilities often did not become known until the youngster was of school age. Now, the demand arises for preschool services.

2. Until special education services became widely available, many parents sought early admission to state residential facilities for their retarded and multiply-handicapped children. Now that most states and many communities have public school services, there are more manifest needs for transportation, for recreational services, for summer programs.

3. With mentally and neurologically impaired youths completing their formal education, the next request is for vocational training and for job opportunities.

4. As larger numbers of developmentally disabled individuals reach

adulthood, they and their families are seeking suitable housing and other community services different from what they required as children.

5. Survival of the disabled also means an increasing number are outliving their families. This leads to new needs in the area of protective services, including financial assistance and guardianship.

PLANNING MECHANISMS

For planning to be effective, it is helpful to have the knowledge and skill of people professionally trained in social and health planning. To be meaningful and appropriate to the problems of the developmentally disabied, however—and to have any substantial hope of successful implementation—it also requires the active participation of a truly representative group of those people most directly concerned.

Often listed last, or omitted altogether, are the people most intimately involved and in some ways the most knowledgeable: the *developmentally disabled* themselves. Their life experiences, their frustrations and their self-perceptions are important ingredients of the goal-setting process; and it is often the disabled who can best speak for themselves.

Because the presence of a disabled child affects the whole family, *parents* stand prominently among the "consumers of service" and should therefore participate actively in the community planning effort. Further, they and other members of the family can often function as surrogates for those developmentally disabled persons who are so young, or so severely retarded, as to be unable to serve as their own advocates.

The experience and insights of *professional* from various disciplines will add understanding and help make the planning process meaningful. Among these are teachers of the developmentally disabled, physicians and other health specialists, social workers, therapists and vocational rehabilitation counselors.

Interested citizens serving as *volunteers* can bring much to the planning process. An International Symposium on Volunteers,[8] held in Philadelphia in October 1971, pointed to the numerous services volunteers can perform, from working directly with the disabled to spearheading social action. Volunteers who have worked with or on behalf of the disabled can become advocates in ways that the disabled, their families and professional workers sometimes cannot, because the volunteers appear to be more objective (and also because they often have contracts not otherwise available).

Beyond the individual participants, in a planning effort so ramified as this, it is advisable to use all organizations and mechanisms that exist in the community or are available to it. Some are readily apparent and eager to cooperate; others require searching out.

There are agencies and organizations at the *local* and the *state* levels (and, often, regional offices of national organizations and Federal agencies). Some of the agencies are *public* (i.e., governmental) and others are *voluntary*. Organizations may be of lay *citizens* or of *professionals* in various fields.

Here are a few examples of organizations and agencies whose help should be available to almost any community. These are listed somewhat at random, they are representative of a larger group of resources that can be utilized:

Local voluntary: The community planning council (often called health and welfare council, or council of social agencies); organizations of the disabled and of parents of handicapped children.

Citizen: League of Women Voters, Jaycees, Civitan, American Legion, PTA Council.

Professional: Local or regional units of American Association on Mental Deficiency, Council for Exceptional Children, National Association of Social Workers, National Rehabilitation Association, State Psychological Association.

Public (local): The board of education (or office of the superintendent of schools); the municipal or county departments of health, welfare, recreation; the county council on mental health and mental retardation.

Public (state): Departments of mental hygiene, education, institutions; office of vocational rehabilitation; comprehensive health planning agency.

Public (regional): U.S. Department of Health, Education, and Welfare.

Some of these groups can supply factual information; others will contribute useful opinions and insights; still others will deliver working volunteers, or headquarters space, or organizational know-how. A number of them are already engaged in social and health planning, perhaps in another sector of the local scene, and their knowledge and conclusions may be relevant to the planning for the developmentally disabled. (What Sieder[16] wrote more than a decade ago about community welfare councils is still pertinent; and likewise the findings and recommendations of the National Commission on Community Health Services[6] with regard to health action-planning.)

There are still other mechanisms, usually at the state level but often accessible to the individual community, which can be useful adjuncts to the local planning effort. How helpful they are will depend partly on the imagination of the planners. One such resource is the state system of higher education. (Lippman and Leibowitz[14] have reported on how the University of California Extension facilitated citizen involvement in the development of the state's comprehensive mental retardation plan.) The adult education programs of the state colleges and local public school systems are other possibilities.

COMMUNICATION MECHANISMS

As already suggested, planning at the community level to serve the developmentally disabled should involve the largest possible number and variety of interested individuals and organizations. The working group and its subcommittees must be kept to manageable size, to be sure; but it is possible—and advisable—to communicate with the larger constituency at crucial stages of the effort.

Among the channels of communication, which may be used to reach the whole community or selected subgroups, are:

Meetings. At an early stage of the planning, various segments of the community (parents, professionals, etc.) can be involved in defining the problems as they see them. Later on, there can be reports from the planning group to the interested public, so that ideas can be tested and refined.

Conferences. Whereas meetings may be as small as two or three people, or as large as an auditorium full of the "general public," conferences are more structured and require extensive planning. It is important to allow for participation by those attending, rather than merely exposing them to a series of speeches or reports.

Mailings. It is useful to develop a mailing list of persons and organizations that have shown interest in the subject. Mailings can be regular or sporadic, brief or detailed, as circumstances indicate. In addition to the sharing of information, there is the sense of involvement which later provides a basis for support.

Newsletter. If the planning is broad-gauged and continues over considerable time, it is useful to have a periodical publication which will keep the constituency informed. This is perhaps less flexible than specially designed mailings, but it has the advantage of putting information on the record for all to see. It is also more economical than some other forms of mailing.

Publicity. At appropriate stages in the deliberations of the planning group, there should be positive efforts at public information and awareness. The mass media (press, radio, television) are obvious outlets, but there is utility also in brochures, exhibits, or a speakers bureau.

Special channels. For more detailed and thoughtful presentation of the ideas as they evolve, there are, in the larger communities, specialized media. Among these are educational television (ETV), the frequency modulation (FM) radio stations, and cable television (CATV). These have smaller audiences than the commercial radio and TV outlets, but with advance promotion it is possible to attract the listeners and viewers who should be aware of the planning effort.

For the planners who wish to reach their public with effective messages, there is a useful resource of ideas and samples: the National Public Relations Council of Health and Welfare Services, 815 Second Avenue, New York, N.Y. 10017.

LONG-RANGE PROGRAM CONSIDERATIONS

It is not enough to plan within a narrow compass; there must be consideration of the implications beyond the immediate and the obvious. To take a few simple examples:

- A plan to establish a facility (such as a workshop) implies a long-range capital commitment. Thus, if a plant is to be rented, a lease must be signed. If the plan envisions construction (and even if the original capital funds are in hand or in sight), there will be later maintenance and perhaps renovation costs. On a smaller scale, the establishment of a facility in a given location may imply a commitment to transportation costs, particularly if there is a movement of the client population within the community.
- It is dramatic and satisfying to bring a new service into existence; but this is not enough. Service to the developmentally disabled is a long-range proposition. Here today and gone next year may be worse than no service at all. Launching of a program, therefore, should include provision for long-term staffing. Needless to say, this also calls for long-term funding.
- As noted above, one new service in isolation is not enough. Any

innovation should be envisioned and planned as part of the continuum of services. Interrelationships should be designed, not left to chance.

In summary, program components, staffing and financing must be considered in relation to one another, and in a longer context than just the hopeful: "Let's get something started. It will prove itself as we go."

PLANNING AT THE REGIONAL LEVEL

The relationship between community needs and state-level services (such as residential facilities) has been mentioned. There is an intermediate stage, which planners at the community level should likewise take into account. The regional (multi-community or multi-county) level is sometimes the most appropriate for the establishment of specialized and relatively expensive services. Depending on geographic distances, size of the population and availability of transportation, for example, an adequately staffed multidisciplinary diagnostic center might be established in one accessible location and utilized by families from a substantial surrounding area.

Even if each community will establish its own facility, it is helpful to discuss the plans with neighboring communities. In a preschool nursery program, for example, there may be need for an audiologist or a speech therapist on less than a full-time basis. It is possible for several programs in an area to share such specialized professional help on an itinerant schedule.

An obstacle to effective planning is the jumble of jurisdictions. School district, health district, coverage areas of other public services, not only are not coterminous in most states, but they often overlap. Short of remaking all the jurisdictional maps–a process which has been tried often but has succeeded seldom–it is necessary to consult with all the appropriate administrative officials (education, health, etc.) to insure that the plan will work when it moves off paper and into the territory. Further, transportation and communication especially may transcend such politico-legal boundaries as city and county lines; and it is advisable for planners at the community level to coordinate with their neighboring counterparts.

A variety of regional planning efforts are already under way in many states. These include the community activities of the state department of mental health, the division of vocational rehabilitation (a Federal-state agency which operates at the regional-community level), and in some states the intermediate school unit.

Finally, with respect to residential services, the limitation of resources makes it unlikely that every community will soon be able to establish its own group homes or other small-scale facilities. Planning for such services, therefore, should be undertaken in close consultation and cooperation with neighboring communities.

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Planning Environments Responsive to New Program Concepts

Michael J. Bednar

INTRODUCTION

In order to plan environments responsive to new program concepts, planners and designers must first begin to understand how individuals with developmental disabilities interact with the physical environment. Likewise, they need to know how various features of the built environment relate to developmental disabilities: which features result in positive benefits and which of them produce negative consequences. There is a RECIPROCITY of influence between man and environment which is the key to planning new, responsive environments. New program concepts then become catalysts for planning action: opportunities to develop environments of responsive reciprocity.

Thus the concern is not with the content of new program concepts nor with the shape of environments to accommodate them. Both program concepts and environments will change. The concern is with the process of programming responsive environments which will evolve as program concepts develop.

The discussion which follows will limit its concern to individuals with developmental disabilities as defined in the Developmental Disabilities Act:

> ". . . a disability attributable to mental retardation, cerebral palsy, epilepsy, or other neurological condition . . . ."[1]

INTERACTION WITH THE ENVIRONMENT

Our first concern in planning new environments is with a realization of how man interacts with his physical environment. In what ways does it influence his life and behavior, his emotions and attitudes?

Environmental researchers are learning more about man-environment interaction each day. The general conclusion appears to be that the environment influences each of us in many ways which we do not realize; ways which are very profound yet beyond our range of awareness. Perhaps this influence can only be summed up in Winston Churchill's profound statement, "First we shape our buildings and then they shape us."

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[1] Developmental Disabilities Services and Facilities Construction Act (P.L. 91-517) pg. 346.

We now have come to realize that environmental quality can affect our health; that excessive noise levels can lead to heart attacks; that the lack of sunlight can lead to skin cancer; that stale air can spread contagious viruses. We also know that the environment can affect our psychological well-being; that the density of people in a room can cause stress and anxiety; that the lack of privacy can cause personality distortion; that the colors of our walls can influence our mood. Who would have suspected that the arrangement of our housing units could determine our pattern of social aquaintances; that the way we sit around a table influences our social communication; that fences around a house establish territorial boundaries which lead to neighborhood feuds. Yet all of these facts have been demonstrated. The physical environment is a pervasive influence, and we must be sensitive to it when we plan and design.

The special concern here is with the effect of the physical environment on the lives of those individuals with developmental disabilities. In many ways, the environmental effects are the same as those for people without disabilities. However, we will concentrate on the differences since there are fewer of them.

Developmental disabilities can be grouped into three broad areas which relate directly to the physical environment:

- PERCEPTUAL DISABILITIES
    - MOTOR DISABILITIES
        - PSYCHO-SOCIAL DISABILITIES

Perceptual Disabilities

Most mentally handicapped have difficulty with perception: with the ability to receive and process information received through the senses. Difficulties with visual perception are the most crucial in terms of environmental perception since it is estimated that we receive 90% of our information through vision. Of secondary, but yet great importance to environmental perception, is hearing. The environmental information received through the sense of touch is third in importance, with taste and smell being of lesser significance.

Individuals with developmental disabilities may have distorted perceptions. They do not receive environmental stimuli accurately or consistently. Their senses do not function in a coordinated manner, i.e., they cannot hear what they see or see what they touch. Their perceptions of the environment become scrambled and their relationship to it becomes confused.

The mentally handicapped have difficulty in focusing their senses to receive the required information for successful functioning in the environment. Their attention wanders; they cannot concentrate; they perceive and process unnecessary information. They may have the disability of sensory hyperactivity. Successful functioning in the environment requires the ability to screen environmental information according to a predisposition for action. In an exaggerated sense, it is like searching for a restaurant while walking along the street. The individual who is sensorily hyperactive might find himself in a clothing store at first, and then pass by the restaurant because he sees a brightly colored service station.

Other forms of perceptual disability do often occur. Perseveration is the inability to shift easily from one perception to another. The stimulus is held in focus long after its information value has been absorbed. The environmental stimulus may actually be gone, but the individual still "sees it in his mind." Dissociation is the inability to perceive things as meaningful wholes. It is literally the inability to "see the forest for the trees"; to make words out of letters; to see a house as more than dissociated doors, windows, and walls.

Figure-background reversal is another serious perceptual disability. It involves reversing the visual field such that the background stimuli take precedence over the foreground stimuli instead of the reverse. This individual has difficulty with depth perception. He cannot judge the distance to an object because the background is perceptually stronger than the object. Indeed, sometimes he cannot even distinguish the object; it becomes part of the background.

Motor Disabilities

Many individuals with developmental disabilities may not have motor disabilities per se in the sense of physical handicaps. However, they may have motor disabilities which are a result of perceptual or mental dysfunction. These kinds of motor disabilities can be termed motor hyperactivity, poor motor skills, and distorted body-image.

Motor hyperactivity is the counterpart of sensory hyperactivity. It can be defined as the inadvertant reaction to all stimuli which produce a motor response. This person cannot control his energetic motor activity. He is constantly "on the go" and seldom at ease. His response to the environment is aggressive and physical.

The individual with poor motor skills is termed "clumsy" and "uncoordinated." He often stumbles, trips, or bumps into things. He has difficulty in moving through the environment with ease especially when there are stairs or ramps.

A consequence of motor hyperactivity and poor motor skills is distorted body-image. This individual has little understanding of the orientation of his body in space. He has difficulty with sense of direction: left versus right, forward versus backward. Likewise, he lacks confidence and pride in his body. Since he cannot control it to perform as required, his image of it becomes negative and distorted. Without an accurate and positive body-image, one's functioning in environmental space becomes seriously impaired.

Psycho-Social Disabilities

The physical environment affects those with psycho-social developmental disabilities in a very profound way. Yet it is this area of influence that is perhaps the least understood by environmental designers.

Psycho-social disabilities are those which relate to the individual's psychological disposition and/or social relationships with peers, family and society. Our society's attitudes towards those with developmental disabilities are reflected in the environment in very subtle ways.

The Developmentally Disabled often have a poor self-concept. They see themselves as individuals who are of little use to the society. They do not know the feeling of success and acceptance. Their image of themselves is not one of an individual who is capable and confident, but one who is weak and a failure. This poor self-concept leads to emotional and psychological maladjustment. It is reflected in the individual's expectations of the environment and the environmental rights which are granted to him.

The social role of the disabled has not been defined as one of the positive contribution. The disabled are regarded as social burdens. They are often not given the opportunity to develop their skills, to become active contributors. Since it is assumed that they have little social value, they are given little control over their environment. They are not allowed to participate in its development or change.

All of this leads to a state of psycho-social malaise; of rejection and defeat. This state of affairs can be counteracted. A positive physical environment is one way of achieving this end.

None of the Developmentally Disabled possess all of the above disabilities in equal measure. Neither do they exist in isolation. More often they occur in combinations, and they are also cause and effect for each other. Motor Disabilities may be cause for Psycho-Social Disabilities and vice-versa. They both may be cause for Perceptual Disabilities.

The important fact is that all of these disabilities cause the Developmentally Disabled to relate to the physical environment in special ways. Moreover, this relationship is different for each of the disabled since his disabilities are present in different combinations. In constructing responsive environments, we must, therefore, seek to identify commonalities among the Developmentally Disabled in terms of environmental interaction.

PROGRAMMING RESPONSIVE ENVIRONMENTS

Programming is a process of relating environmental variables to human needs. Programmers must understand those needs, in this case the special needs of the Developmentally Disabled. They must also be knowledgeable about the environmental means available to accommodate those needs. A programmer is not only programming the physical environment but also the people who use it. He is in fact programming their actions and responses to that environment. He is establishing the basis for effective environmental reciprocity.

Developmental disabilities have been discussed in terms of their components for environmental interaction. Now, one must look at the physical environment itself, to see which of its characteristics are related to developmental disabilities. An understanding of both halves of the man-environment dualism is necessary for effective programming.

All human beings have certain requisite environmental needs which are universal:

Climate: oxygen laden air, critical temperature range, dryness, control of air movement

Space: space to perform required activities, space to house required equipment and furnishings

Environmental quality: light quality and quantity appropriate to function; required level of quiet and sound deadening

Stability: environment which resists structural loads and natural forces (storms, earthquakes, hurricanes)

The provision of these environmental needs are generally well accepted, although we are not always successful in satisfying them in every building.

Our particular concern here is with those special environmental needs which are a resultant of developmental disabilities. In general these needs are in the realm of the psychological and sociological. Thus they relate to those aspects of environment which are connotational and interpretive; which are implicit rather than explicit.

The set of Environmental Characteristics which relate to the needs of the Developmentally Disabled are presented here as bi-polar continua. They are based upon previous work by myself and others (Bayes,(1) Bednar & Haviland,(3) Brill(4)). Many of the effects of these characteristics have been confirmed by educators and psychologists through observation if not research studies. Architects have confirmed the fact that these characteristics can be controlled through design. However, much more work is needed to develop these concepts into more useful tools. Examples of each characteristic will be provided from a recent study tour of facilities for the handicapped in Denmark, Sweden and Holland (Bednar, 1972).

ENVIRONMENTAL CHARACTERISTICS

1. **Accessible** .... **Inaccessible**

   Accessibility can be defined as the physical and psychological ease of approaching and entering an environment. At 'T' Hont in Veldhoven, Holland the administration building of this institution is an old house located no more than 50 feet from the main street of the town. It is both physically and psychologically Accessible. On the other hand, the new Central Institution for Children in Nyborg, Denmark is isolated in the countryside on a second-class road with farms surrounding it. The town and institution are separated by a large park, making it Inaccessible.

   Access is a necessary prerequisite for participation in an environment. The provision of Accessibility can promote the sense of social acceptance and a stronger self-concept. A clear expression of access may also aid to overcome perceptual difficulties. On the other hand, control of access may be necessary to limit the behavior of the individual who is motorically hyperactive.

2. **Familiar** .... **Remote**

   These are qualities of a setting which relate it to other settings with which the user has had previous experience. The user in a Familiar setting knows what to expect and how to function. Remote settings are new and different;

they may cause anxiety. Storhagen in Akersberga, Sweden is a nursery school and home for 27 young handicapped children. The environment is very Familiar since the institution consists of 5 converted row houses in a group of 70 row houses. The institution is the same as the surrounding residential environment. On the other hand, the Brondbyoster Home near Copenhagen is a very Remote environment to live in, because of the exposed concrete and pipes in the living and dining rooms. This environment is not like their parents' homes; it is Unfamiliar or Remote.

Familiarity with the environment "breeds" self-confidence and security. The individual feels more "at home." It may also aid perceptual functioning since he is accustomed to perceiving environmental information in a Familiar setting. An extremely Remote setting can foster anxiety and motor hyperactivity because it makes the individual ill-at-ease. Too much familiarity causes complacency; some measure of remoteness provides health stimulation.

3. **Formal** .... **Informal**

This bi-polar continuum measures the degree of behavioral control which is exerted and communicated by the environment. A Formal setting sets forth explicit behavioral rules through a system of environmental cues which are commonly interpreted. S'Konings Jacht in Schaarsbergen, Holland is an institution for severely and profoundly retarded. In the residential pavilions, each bedroom, shared by four children, has been attached directly to the bathing-toileting area. This is a very Formal setting since the pattern of activities has been strictly prescribed by the architecture. Perhaps the most Informal settings in Denmark are the adventure playgrounds which are built by children using discarded materials. A wide range of behaviors is encouraged by these settings.

The degree of Formality - Informality to be included in the design of an environment must be carefully related to the developmental disabilities of the occupants. The appropriate degree of Formality - Informality will promote self-confidence through the environmental support which it provides. Too much Formality will place unnecessary restrictions upon the opportunities of the individual to develop. Too much Informality may foster both sensory and motor hyperactivity through the lack of environmental controls.

4. **Sociofugal** .... **Sociopetal**

This characteristic measures the degree of environmental support for social interaction. A Sociopetal plan encourages the development of social relationships by drawing people together. It is centripetal in tendency directing people towards the center of an environment, where they can meet. A Sociofugal plan discourages social interaction by keeping people apart. It is centrifugal in tendency and directs people to the perimeter. At the Central Institution for Children in Nyborg, the children's bedrooms are along a corridor with the dining and living rooms at one end. This arrangement is sociofugal in tendency, although not to a strong degree. On the other hand, at the Brondbyoster home for retarded children, the bedrooms are arranged on 3 sides of the living-dining area, and they open directly on to it. This is a strong Sociopetal arrangement.

This environmental dimension relates to individuals with psycho-social disabilities. The careful use of this characteristic can aid in structuring social relationships and controlling undesirable social encounters. The value of the designed environment as an instrument of social therapy is not yet well understood.

5. Private .... Public

The degree to which a user must share a setting with others, both physically and psychologically, is a measure of this characteristic. A Private setting is one in which the exposure to others is limited, usually through unshared use. It need not be exclusively used; only unshared in use at the same time. A public setting is one which is shared with others in simultaneous usage.

The degree of Privacy required for given activities is prescribed by the society. In our society, sleeping and toileting are very Private activities. Private settings for these activities have been achieved in the Danish institutions for the retarded. Single person bedrooms each with a wardrobe and locked door are the environmental standard. Toilets are usually shared by two residents.

Shared settings for Public activities are also necessary and appropriate. In the Danish institutions public facilities have been provided for each house group of 12 in the form of a living room, dining room and outdoor play court.

There is no functional equivalent for the essential quality of Privacy. Environmental Privacy is necessary for good mental health and the development of personal identity. An individual must have the opportunity for Privacy to learn to know himself, i.e., to develop his self-concept. To give an individual Privacy is to place trust in him, to enhance his role as a member of society.

6. Territorial .... Communal

Territorial environments provide support for Territorial behavior, i.e., the possession and defense of environment for exclusive use. Communal environments encourage sharing in use, possession, change, and maintenance. Individuals defend their environments by personalizing them, by giving them an identity which is linked with their personality. When retarded children in Denmark were given a private bedroom, they were encouraged and permitted to decorate it by themselves. When several house units of identical design were clustered together, each group would decorate their house in a unique manner. In Communal areas such as gymnasiums and canteens, this Territorial behavior was neither encouraged nor supported by the design configuration.

Territoriality is closely related to Privacy in that both supply the opportunity to develop personal identity. Emotional and social stability comes from having faith in one's value as a person. Difficulties with social role and self-concept can be ameliorated with the opportunity for territorial expression in the environment.

7. **Oriented** .... **Disoriented**

Orientation, as an environmental quality, supports an individual's identity in space and time through movement. To know where you are, where you have been, and where you are going is important to successful spatial functioning. An Oriented environment encourages space-time identity by ordering movement through spaces such that progression is revealed. Long corridors with identical doors spaced evenly along identical walls cause Disorientation, because there is no identity to movement. Environments which are designed on the basis of space-time interdependence foster space-time identity or Orientation. Activities which are adjacent in time should also be adjacent in space, thus revealing a space-time order.

The design of 'T' Honk Institution for retarded children in Veldhoven, Holland had been based upon the need for Orientation. Facilities which are communal, such as swimming pool, lounge, therapy room, and cafeteria all look out onto an orienting plaza. House groups were placed along an orienting interior street which was designed with squares, alcoves and views to the outside. An example of Disorientation can be found in the "Green Schools" developed in Denmark. These were created on each school site by assembling prefabricated unit modules of equal size and exterior appearance, joined together by covered walkways. Each module houses a different function, but they all look the same. There is no basis for exterior Orientation.

Orientation in the environment can aid in overcoming many forms of developmental disabilities. It can facilitate perceptual functioning by alleviating sensory hyperactivity and perseveration. It can strengthen motor functions through confidence obtained from successful movement experiences. It can bring emotional stability through knowing that "I won't get lost." Orientation is a valuable therapeutic tool which needs to be carefully considered in programming.

8. **Crowded** .... **Uncrowded**

Crowding is a measure of the degree of spatial, acoustical or visual intrusion. Spatial intrusion is infringement upon one's personal space bubble. Acoustical and visual intrusions are infringements upon one's activities through noise or visual distractions. A Private setting is usually Uncrowded but an Uncrowded setting need not be Private. At the Bollmora Institution for physically handicapped children in Tyreso, Sweden, the residents participated in social programs and entertainment in a large open plan living room which produces instances of Crowding. At the Villa Home in Johannesdal, Sweden, 5 children live in a single family detached dwelling in a residential neighborhood. This situation was distinctly Uncrowded, in that each individual pursued his own sphere of activities without disruptions.

Crowding produces problems of perceptual overloading. For those who cannot focus their senses and/or screen out unwanted stimuli, Crowding produces no relief from this disability. Uncrowded situations are generally desirable as long as lack of stimulation is not the result.

9. **Ambiguous** .... **Consistent**

The dimension of Ambiguous - Consistent measures the degree to which a user can place confidence in his interpretation of environmental cues. An Ambiguous environment is one which is not perceived clearly, thus causing misunderstanding, frustration and confusion. A Consistent environment promotes confidence, security and self-reliance.

Some common sources of Ambiguity in buildings are the following:

1. Floor to ceiling glass panels which are neither window nor wall and produce confusing reflections.
2. Highly polished floor surfaces which seem to make people "float."
3. "Fake materials" such as woodgrained plastic, brick patterned linoleum and plastic plants.
4. Exterior materials which are used inside a building (brick, stone, concrete) cause confusion between inside and outside.
5. "Illusionary design" such as walls which fold, false fireplaces, and false panels.

A Consistent environment is one in which colors have been used in a rational way. For example, exit doors are red, office doors are blue, and bathroom doors are orange. Structural integrity in a building imbues it with Consistency. A direct structural expression which reveals the transfer of loads creates the most confidence. Consistency of design in window hardware, door hardware, stair railings, and light fixtures leads to a sense of security in one's environment.

There is a fine distinction between Ambiguity and Consistency. An environment can be so Consistent in its design that it becomes Ambiguous. For example, if all of the doors in a building are the same, confusion can be the result.

"There is almost universal agreement on the necessity to avoid ambiguity in buildings for emotionally disturbed and mentally subnormal children (Baynes, 1967). Ambiguity fosters perceptual distortion and figure-background reversal. Consistency in the environment has therapeutic value in alleviating perceptual problems.

10. **Articulated** .... **Fluid**

Articulation in the environment is the degree to which distinctions between activity spaces are expressed. The traditional school with classrooms along a corridor is an Articulated environment whereas an open plan school is a Fluid environment. The concern in this case is with the degree of separation and/or transition between spaces. The site plan of Vangede Children's Hospital in Copenhagen is highly Articulated. There are detached buildings for each function; kindergarten, administration, residential wards, clinic, and school. The Central Institution for Children at Nyborg is a megastructure. There is less Articulation and more fluid connection of spaces and functions.

The use of Articulation and Fluidity in environments for the Developmentally Disabled is currently under investigation. The use of Articulation in controlling sensory and motor hyperactivity has been quite well established. It was also considered to relieve dissociation and perseveration by providing perceptual order in the environment. Recently, some open plan schools have been built which maximize upon the quality of Fluidity. They are being used with success in educating emotionally disturbed and mentally retarded children, although final results have not yet been confirmed.

The proposal being made in this paper is for a new dimension to the environmental programming process. This new dimension focuses upon relevant relationships between the nature of developmental disabilities and characteristics of the designed environment. This new dimension goes beyond the specification of square foot areas, lighting levels, climatic conditions, acoustic levels and material durabilities. It begins to specify the more general yet pervasive qualities of environment which are seldom included in programmatic statements. This proposal is in accordance with Constance Perin's redefinition of the design program as "... A conceptual scaffolding between environmental design and the human sciences" (Perin(5)). "A design program developed in this way will specify so many previously unacknowledged human requirements that the designer is challenged to develop responses going beyond those presently in the vocabulary of forms" (Perin(5)). It will result in a *new architecture* for the Developmentally Disabled.

The qualities represented by the Environmental Characteristics presented here need to be programmed in accordance with the user's developmental disabilities and the new program concepts designed to service his needs. They need to be discussed and specified early in the environmental planning process by the programming team. The program of those characteristics needs to be communicated to the architect in terms which are meaningful to him as a designer. If this is done, he will have a sound basis upon which to begin the design process. The designed environment will then be consciously planned to become a positive influence upon the lives of the Developmentally Disabled rather than a negative consequence.

BEYOND PROGRAMMING

The main body of this paper has discussed the reciprocity between developmental disabilities and environmental characteristics. It has suggested that environments can be programmed to provide positive support for these disabilities. The environment can be "tailored to fit" individuals and their needs. However, it is neither wise nor possible to provide a perfect "environmental fit," for several reasons:

1. ***The needs of the individual change*** as he develops and grows; the static environment is not responsive to this developmental progression.

2. ***There is disparity between individual needs and group needs.***

3. ***The population changes;*** new individuals with new needs come to use the environment.

4. ***Program concepts change;*** new techniques of treatment, therapy and education are continuously developing.

The only alternative for the programmer is to provide FLEXIBILITY. He must program the environment to fit generic ranges of needs rather than specific needs. He must anticipate changes in needs and provide for their environmental accommodation.

The designer can provide Flexibility in two ways:

1. ***Physical Flexibility:*** He can provide mechanical means for changing the environment. These means are technologically feasible in the form of folding walls, movable partitions and flexible light and climate controls, as examples.

2. ***Use Flexibility:*** He can provide high quality generic environments which can be used for many purposes. The basic environment remains stable, and flexibility is achieved through modifications in furniture and furnishings.

The architect will probably utilize a combination of these two means to provide the client-user with opportunities for environmental change. However, in order to provide the required degree of Flexibility, he first needs to know the probability of future changes in function and program. These probabilities must be specified by the programming team.

Once the possibilities for flexibility have been provided, of critical concern is the use of those possibilities. There are many examples of Flexibility, which once provided is either unused or improperly used. Robert Sommer, in his book *Design Awareness,* suggests that the architect should provide follow-up consultation on a building which he designs (Sommer(6)). He should provide the client with guidance on how to use the building and how to make adaptations. He could at the same time make evaluation studies to determine how the building is performing. The architect in this case could become a living "set of instructions."

There exists little available specific knowledge about the effects of the physical environment on the lives of the handicapped. It is not yet possible nor may it ever be possible to program and design for every eventuality.

The evolutionary development of residential accommodation for the mentally retarded in Denmark provides a good case study example of this reality. Single bedrooms for mildly and moderately retarded patients were first provided in Denmark by Architect Jens Malling Pedersen at the Central

Institution in Brejning. These houses for 24 patients were designed as four groups of six patients each, all in single bedrooms with their own wardrobe and wash basin. Living and dining facilities were shared by 12 patients. There was a great deal of resistance to this progressive design. However, the results have been very gratifying in terms of patient well-being and development. As an experiment, severely and profoundly retarded patients were also moved into these houses. They too functioned at a higher level than in their old environment. Now an even more progressive experiment has been executed at Logumgaard Institution in Logumkloster, Denmark. Here four small houses, each for five patients in single bedrooms, have been grouped around a garden. Each house is detached and independent in its facilities. Each "family" of 5 cares for itself in terms of cleaning, washing clothes, personal hygiene and socialization. The experiment has been deemed a great success and more groups of houses are being built.

It is only through the efforts of creative programmers and designers that imaginative environmental proposals will be made and executed. Their subsequent evaluation will provide feedback which will advance the knowledge of environmental reciprocity.

We cannot afford to wait until all of the environmental research has been completed before we begin to program and design new kinds of environments. Too many buildings will be built in the meantime which are based on old concepts. We must immediately intensify the process of innovative programming, design and evaluation so as not to burden future generations of the Developmentally Disabled with unresponsive environments.

RECOMMENDATIONS

Both discussion sessions which reviewed this paper overwhelmingly supported its content and approach. The concern for providing environmental *quality* is a major issue in implementing new service concepts for the Developmentally Disabled. Environments of superior quality, which are called for in this paper, will in fact aid in effectuating normalization. Environments which are today construed as "normal" are in fact inferior in quality for both the normal and disabled population. A marked improvement in environmental quality is necessary to realize the full potential of new program concepts.

The value of the Environmental Characteristics as tools in programming and planning was immediately recognized. They can be used in remodeling existing facilities as well as planning new facilities. They are valuable because they start with basic values rather than accepting prototype solutions. The only hope is for substantial future support in sponsoring environmental and behavioral research to further develop these initial considerations.

Several issues received considerable attention during the discussion sessions. They are summarized here in the form of Recommendations to the State Advisory Councils for the Developmentally Disabled.

RECOMMENDATION 1: The Physical Environment Should be Considered as a Critical Component in the Developmental Disabilities Service System

The physical environment should be considered as a positive contributor to the realization of program goals, and it should be planned integrally with other service components. Inappropriate physical environments can prohibit successful implementation of program concepts. They can create additional long term service costs which detract from efficient delivery of services.

It is hard to avoid using a building which has been built, even if it is inappropriately conceived. Unusable physical facilities need to be avoided through effective early planning.

The options for delivery of facilities as service components need to be thoroughly explored. One has the choice of building or not building, or leasing or buying facilities already available. If the decision is to build, there are many choices of what to build and where to build it. There is an existing trend towards decentralization in the delivery of developmental disability services. The perpetuation of centralized facilities are counter to this trend. Likewise, there is a trend towards development of a hierarchy of care services. Existing institutional facilities can have a negative effect on implementation of this delivery concept.

RECOMMENDATION 2: The Process of Planning Physical Facilities Must Be Carefully Restructured to Produce Responsive Environments.

The process of planning facilities has profound implications for the resultant architectural form. The participants in planning, the information available, and the decision process needs to be restructured in the light of new program concepts which require new kinds of physical facilities. Most existing planning processes are organized to produce large institutional facilities. New processes are needed to provide decentralized facilities which are flexible in use and efficient in cost.

State Advisory Councils should carefully evaluate existing facility planning processes and seek to effectuate necessary changes. They should understand how and when critical environmental decisions are made, such that important decisions are neither overlooked nor made by default. They should seek to establish linkages in the process between conceptualization and implementation.

There is confusion in most existing planning processes between the planning phases used by program administrators and those used by architects. Comprehensive Planning of services is the counterpart of Master Planning of physical facilities. Program Development is the counterpart of Environmental Programming and Design. Delivery of Services or Implementation is the counterpart of Construction of physical facilities. New planning processes and attendant legislation must recognize the relationships between these phases such that integrated planning of programs and facilities would take place.

RECOMMENDATION 3: State Advisory Councils Should Obtain Architectural Expertise During All Phases of State Planning for Developmental Disability Services.

Since integrated planning of facilities and services is deemed crucial to improvements to existing delivery systems, architects should be involved in comprehensive state planning for developmental disabilities. Architectural expertise will be invaluable in planning site locations, size of facilities, re-use of existing facilities, phasing of construction, and construction budgets. After comprehensive planning, his expertise will be needed during programming of specific facilities in terms of discussing design alternatives and establishing environmental design priorities. His presence will insure that design decisions are not left to be made by default.

The Developmental Disabilities Services and Facilities Construction Act (P.L. 91-517) provides grants for technical assistance in planning, under Sections 103(d), for the above purposes.

RECOMMENDATION 4: State Advisory Councils should Actively Consider the Re-Use of Existing Public and Private Facilities to Accommodate Developmental Disabilities Services.

The re-use of an existing building provides many advantages. It saves a great deal of time, in comparison to new construction. More space is usually available for less cost, even after remodeling has taken place. Existing facilities usually occupy desirable sites which are part of an existing community. The re-use of a facility can provide opportunities for flexibility in the delivery of services.

An architect should be actively involved in selecting facilities to be re-used as well as designing the adapted facility. The problem of facility re-use is in many cases a more complex problem than new construction. It requires professional guidance.

RECOMMENDATION 5. Cost Effectiveness in Facility Provision and Use Should be a Primary Goal.

Cost Effectiveness refers to a broad based consideration of all cost factors in facilities planning. High long-term maintenance and operational costs should not be overlooked in favor of low initial construction costs. Land costs should be evaluated in terms of attendant building costs related to building heights, utilities and construction standards. Access costs must be studied relative to land costs. Slightly higher initial construction costs necessary to provide flexibility of re-use may be economically advantageous over the long run. Trade-offs between cost factors must be carefully considered before cost decisions are made.

The concept of providing fixed location facilities with a 50 year life severely limits opportunities for cost effectiveness. The segregated institutional facility requires a long-term commitment to operation and maintenance costs. Implementation of new program concepts may be limited due to this high fixed cost commitment. Effective facility planning can, in fact, be a useful cost control tool.

RECOMMENDATION 6: The Provision of Maximum Flexibility Should Become a Primary Goal in All Planning for New Facilities.

The inclusion of flexibility in facility planning is an economic and logistic necessity. Static physical environments cannot respond to dynamic program development. The users of a facility want evermore to participate in its development and change. Populations to be served change in character and number.

Different opportunities for achieving flexibility are available, as discussed earlier in this paper. These alternative opportunities need to be explored and incorporated into the planning process. The objective must be to keep the physical environment from getting in the way of program development, i.e., to make it a supportive service component.

The inclusion of flexibility does not require the construction of warehouse or loft space. Flexibility and environmental quality are not necessarily mutually exclusive objectives, as long as planning for them is coordinated.

Most of these Recommendations were not put forth as formal proposals by the discussion groups. However, they do reflect the intentions of the panelists and discussion participants. It is my hope that they be seriously considered by all State Advisory Councils during development and evaluation of State plans.

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Essentials of Program Evaluation

Donald J. Stedman and Richard C. Surles[1]

In a recent talk[2] given to the Department of Health, Education, and Welfare employees by Secretary Elliott Richardson, special emphasis was placed on the importance of planning and evaluation in program development and service delivery systems. This special stress on evaluation and precision in program operations was not meant only as a recommendation to improve decision making. True, it underlined the increasing need to make best use of our human and fiscal resources, to improve the quality and increase the number of services available, and to make more effective the programs we already have. However, the major theme was that evaluation sharpens our focus, enhances greater flexibility, provides more time for leadership, and *encourages change.*

That insight startled most people who saw planning and evaluation as simply a culturally acceptable method of meeting compulsive needs. It extended the imagination of those who see only increased accountability in procedures which pinpoint the one who drops a deadline or bobbles the budget.

A system for encouraging change! We hadn't planned on that.

As a consequence we can approach program planning and evaluation with a new vigor, freed from the notion that planning is somehow meant to stall things off until the problems go away. Or, that evaluation is research meant to be critical and punitive like an Inspector General. Planning is setting clear goals for action. Evaluation is testing whether you met those goals. There are alternative ways of going about both but one simple route will be presented here. You may find your own favorite model later but it will only be a variation on this one—not a different one. The model includes *eleven* essentials. They are presented here as interrelated components of a *system* for planning and evaluation. You can use it yourself on almost any planning task whether external or internal to the organization.

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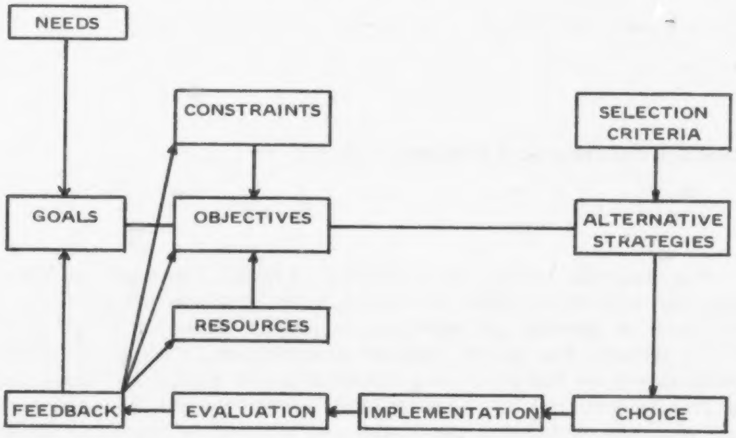
*This working paper draws heavily upon recent work by J. J. Gallagher and R. Surles at the University of North Carolina, Chapel Hill. An expanded manual on program planning and evaluation is forthcoming from these authors soon.

[1] Dr. Stedman is Acting Director of the Developmental Disabilities Technical Assistance System. Mr. Surles is Associate Director for Program Planning and Evaluation.

[2] Richardson, E. L. Responsibility and Responsiveness: The HEW Potential for the Seventies. DHEW Publication OS-72-19, January, 1972.

Chart #1

PROGRAM PLANNING AND EVALUATION MODEL



Gallagher, 1972

Essential Elements

Reference to Chart 1 indicates that *needs* alert us to change potentials. Needs then generate *goals.* Goals require specified *objectives.* Objectives can only be met or realized within the boundaries of *resources* matched against *constraints. Strategies* for reaching objectives, selected from *alternative* approaches, lead to a *choice* of action, an *implementation* activity, an *evaluation* of the success of the strategy, and *feedback* of evaluation data to adjust goals, improve resources, sharpen objectives, or reduce constraints . . . a neat *systematic* flow.

The cycle continues, providing a dynamic activity, feeding our experience back into our work, improving the decision making, the operations and the product.

Each essential element is defined below:

1. ***Needs*** – Areas of perceived void or lack of services.

2. ***Goals*** – General statements revealing assumptions made about expected outcomes of an organized program. Goals identify a program area, its targets, purpose and expected results.

3. ***Objectives*** – Specific statements written in measurable terms which describe a target population, treatment to be given, results expected, expected completion dates, and specific individuals who will accomplish the tasks.

4. Resources – The human, technological and organizational materials available for use in meeting goals and objectives.

5. Constraints – Factors which limit the scope and feasibility of objectives (e.g. lack of funds, limited supply of trained personnel).

6. Strategies – The "plans for action," the methods or procedures for determining what activities will be used.

7. Selection Criteria – Bases for the selection of the particular activities or operations.

8. Choice – Selection of operational strategy or plan of action.

9. Implementation – Initial operationalization of strategy or putting the operational plan to work.

10. Evaluation – Delineating, obtaining and providing useful information for making decisions concerning the program components or results of activities.

11. Feedback – Information from evaluation which has implications for future activities or planning.

Now let's see how the model works through an example that focuses on planning an evaluation system for a social service project. Although the example emphasizes evaluation, it would seem that planning problems such "how to select handicapped populations for programs," "how to staff," "how to design a curriculum," or "how to find additional funds" could also be analyzed using this model.

Example of Model

Need: An evaluation plan must be developed and carried out.

Goal: The plan must meet state requirements, and must provide information to the public about the effectiveness of the program.

Objectives:

1. to complete the evaluation plan by September 1.
2. to begin collecting data by September 15.
3. to complete data collection by April 30.
4. to complete the data analyses and to file a final report by June 1.
5. to prepare a brief report for public dissemination that will outline the successes of the project.

Constraints:

1. $2,000.00 is budgeted for evaluation.
2. teachers are reluctant to participate in an evaluation.
3. no one on the staff is familiar with data analysis (i.e., statistics).

Resources:

1. $2,000.00 is budgeted for evaluation.
2. A firm can provide consultative assistance in evaluation.
3. A college in town has graduate students who could help with the data analysis.
4. An evaluation consultant will help develop the plan.

Alternative Strategies:

1. Director hires a consulting firm to develop and carry out evaluation plan.

2. Director seeks an additional staff person who would devote one-fourth time to evaluation.
3. Director attends workshops on evaluation and develops plan.
4. Director uses the staff in conjunction with the consultant.

Selection of Criteria:

1. The consulting firm wants $1,700.00 to create and do data analysis.
2. Director wants to allocate at least $500.00 for printing and dissemination of data but could get by with $300.00.
3. The consultant says that he will set up the plan (objectives and evaluation methods) and provide graduate students for purpose of data analysis for $1,000.00.
4. Teachers know and trust the consultant.
5. Graduate students will be qualified testers and will not interfere with classroom activities.
6. With the extra $1,000.00 Director can hire a consultant to help decide how best to format and distribute data.

Choice: Director hires the consultant and graduate students for $1,000.00 and closely supervises their activities.

Evaluation:

1. Director checks to see if the following events occur as planned:
    a. evaluation plan by September 1
    b. collecting data by September 15
    c. data collected by April 30
    d. report by June 30
    e. 2 page data sheets ready for dissemination by June 30
2. Director seeks information about the quality of the report to them.
3. Director plans to hire an independent consultant from next year's budget to study the impact of public dissemination of data.

Feedback:

1. A budget of $2,000.00 for evaluation is probably too small.
2. Director needs to find out how other project directors are handling this problem.
3. Director needs to hire a person for next year who could serve as an administrative assistant and as the Director of Evaluation for the project.

A factor to consider is that, in actual operations, most of us probably work with problems in which we have some vested interests, expertise, and experience. For example, a person might begin working with preschool deaf children because he has been trained in deaf education, has worked with other deaf children and has come to believe that the younger he can work with them the better for the children. In such an example, this individual would probably enter the planning process with "alternative strategy," "selection of criteria," and "choice" already determined. The problem-solving approach, in this case, would be to define the parameters of the other seven elements in the planning model.

In effect, then, the model describes a series of structures, indicates that those dimensions are interrelated, and allows the planner to fill in the "blanks" with information that fits his needs. It is intended as one way a project director and/or planner might begin to conceptualize what has to be defined and accomplished. It is not intended as an ideal of how one plans, nor as an example of a theoretical hierarchy of planning. In fact, entry into planning is probably a very random process and the model present planning elements in an *artificial* order.

Having walked through the model, let us now examine which elements are most essential to the planning and the subsequent evaluation process. Special emphasis needs to be placed on the features of *goals, objectives,* and *evaluation.*

In the process of planning for evaluation, special attention needs to be given to the development of goals and objectives.

Goals and goal statements are used by a project to highlight its intentions. In other words, goals specify what will happen to a target population as a result of services developed. Goals are abstract and are often based on assumptions and value judgments, but they do give the general direction and purpose of the project activities. However, goals do not lend themselves to evaluation statements.

In order to move toward precise evaluation, more specific intentions which include measurable indices and time limits are necessary. This requirement is accomplished by stating objectives which describe what will be done by the project during its operations and how they are related to the goals. The assumption is made that if a positive evaluation is made of the specific objective results, then the project is in the process of meeting its goals.

Objectives are described as either *administrative* or *outcome* objectives. Administrative objectives indicate the administrative strategy used by the project and reveal the management approach to be utilized in meeting the outcome objectives. They indicate what has been done or what will be done in project operations, including when, by whom and by what success index the objective will be evaluated. On the other hand, outcome objectives reveal expected changes in behavior or attitude of the target population. The evaluation of effectiveness of the project becomes a major concern when attempting to describe the results of these objectives.

The following three charts should help to clarify the distinction between goals and objectives by providing examples and a dimensional overview.

DISTINCTION BETWEEN GOALS AND OBJECTIVES

Goals	Objectives
Show general intent and direction.	Some specific intentions with measurable indices and time limits.
The project will improve language development in young handicapped children. The project's parent program will increase parental involvement with children.	To improve, beyond normal expectations, the receptive vocabulary and complexity of expression in retarded children in our center by June 1, 1973. To increase over baseline performance parental verbal interaction (nonhostile) with child by June 1, 1973. To develop a language curriculum for three year old language-impaired children by November 1, 1973.

DISTINCTION BETWEEN ADMINISTRATIVE OBJECTIVES AND OUTCOME OBJECTIVES

Administrative Objectives	Outcome Objectives
Useful for program management and progress reports.	Represent final statements of expected project benefits. *Final* report materials.
To establish a parents' counseling group that meets once a month during 1973.	To increase parents' personal interactions with their children by 25% over baseline by June 1, 1973.
To hire three qualified speech teachers and two aides to deliver service to the children by May 1, 1973.	To improve by a statistically significant amount the language skills of children in expressive language during this school year.

DIMENSIONAL OVERVIEW OF GOALS AND OBJECTIVES

	Goals	Administrative Objectives	Outcome Objectives
Time Span	Extensive (years)	Brief (months)	Moderate (1 year)
Content	Reveals assumptions being made about the future effect of project's program treatment.	Reveals events which must occur before program outcome can be achieved.	Reveals behavior or attitude changes which are a result of program treatment or activity.
Evaluation	Expert Review	Frequency Count "Yes/No" Log Check List Criterion Reference	Psychological test "Homemade" test Criterion Reference Frequency Count Testimony
Number	Few (2-3)	Many (10-20)	Several (4-6)

After the objectives have been clearly stated—including measurable statements of intent—an evaluation strategy can be undertaken. Strategies may vary; but, generally, evaluation will provide a decision maker with information about (1) the merit of plans, (2) the processes being utilized, or (3) the product that has resulted from activities.

The evaluation of the merit of plans provides information about the worthiness of goals, objectives and strategies. It is usually referred to as input evaluation and is usually accomplished by the use of expert review or outside consultation.

Evaluation of processes being utilized occurs when operations of the project are monitored to assess whether activites, strategies and other operations are working on a daily basis as planned. *Process evaluation* data can be summarized to assess how well the project is doing in meeting its objectives and can therefore be used to provide information for product evaluation.

Product evaluation is a summary of information taken over an extensive period of time and reveals information about what a target population was like when a program started and what the population was like after the activities of the project were complete. Process evaluation focuses on the effects of treatment of individuals over brief periods of time; product evaluation is used to produce data about changes among groups of people over long periods of time.

Some examples of both process and product evaluation are provided on the next page.

EXAMPLE PROCESS EVALUATION

Outcome Objective	Strategy	Monitor	Sample Data
To increase each child's self-help skills to that by June 1, he can feed himself without the aid of others.	Child able to feed self.	Anecdotal record for one child.	Oct. 1 — Child can feed self finger food. Oct. 4 — Child interested in holding spoon, but not able. Oct. 10 — Child holds spoon poorly, drops often.

EXAMPLE OF PRODUCT EVALUATION

Outcome Objective	Strategy	Monitor	Sample Data
To increase each child's self-help skills so that by June 1 they feed selves without the aid of others.	Children able to feed themselves unaided.	1. Pre-post observation of criterion behavior. 2. Anecdotal record.	On November 1, only 10% of the children could do the eating activities unaided (N=25). By June 1 96% of the children were eating without the aid of others.

The components of evaluation having been examined, it is important to emphasize the difference between evaluation and research. *Evaluation is not research.* Some research is evaluative in nature but research pursues specific questions. Evaluation is designed to develop data to provide information about the effectiveness or quality of an operating project.

The most crucial task of the Developmental Disabilities Council and its staff will be to develop and continually update a comprehensive statewide plan for delivering services to the handicapped. It cannot be done without a program planning and evaluation system. Haphazard program development is costly, ineffective, energy sapping, demoralizing, and results in endless chaos leading to social and political heat. Systematic, objective program development harnesses resources, clearly allocates responsibility and accountability, encourages change, increases the quantity of services with the same resources, and best meets the needs of the handicapped.

Evaluation of the Impact of State Developmental Disabilities Programs

Seldon P. Todd

INTRODUCTION

The purpose of this paper is to discuss how State Developmental Disabilities (DD) Programs structure evaluations of programs serving the DD population within the respective States. This topic presents a dilemma. On the one hand I believe that evaluation is essential to the effective on-going planning and management of State DD programs. Consistent with this philosophy, state plans under P.L. 91-517 require a description of the methods that will be used to assess the effectiveness of state programs under the plan. On the other hand, it is my opinion that comprehensive rigorous evaluative research of state DD projects is impossible within current state DD budgets. Further, given the current scale of state programs, it is questionable whether it is useful to divert major portions of state DD budgets to evaluative research. However, evaluation should not be abandoned. Thus, this paper attempts to wrestle with the impossible question of how to do our essential job with inadequate resources. The question is not solved here, but hopefully, some useful ideas are presented.

Implicit in the discussion which follows is the notion that evaluation is worthwhile only if it is useful, that resources are scarce from a practical point of view, and that useful information can often be obtained without elegant scientific evaluative research. Emphasis on the practical has been sought.

The ideas presented are the sole responsibility of the author who is a generalist and *not* a specialist in either the field of evaluation or developmental disabilities.

WHY EVALUATE?

Evaluation is an important and serious business. In part it is a highly technical business but in basic concept very simple and straightforward. Its importance is indirectly indicated by the fact that the scale of HEW budgeted expenditures for evaluation for 1972 ($9,110,074) is more than half the total authorizations for the Developmental Disabilities Services and Construction Act for the same period. Its complexity is suggested by the fact that we now have career professionals at the Ph.D. level specializing exclusively in the area of social program evaluation as well as a number of contract research firms dedicating their total energies to this field. Its complexity is also suggested by the fact that in spite of all of HEW's activities in this area there is unknown to the author any articulated philosophy within HEW as to what should be evaluated, how, and for what purpose.

The theme of this paper is that evaluation can usefully be viewed by program planners and executives in a very practical way. In this practical sense, evaluation can be viewed as providing information feedback which is useful to program planners and decision makers in maximizing the worth of the programs for which they are responsible. If evaluation is defined and conducted in this way it will offer a useful tool.

Practical constraints are clearly imposed by the existing budget for the Developmental Disabilities Program which contains very limited resources which can be used for evaluation.

A useful way to start a quest for a practical approach to evaluation is to define evaluation, examine the types of evaluation, and consider the use of evaluation in supporting decisions. Stressing the practical, it seems also useful to consider the question of the degree of threat posed by judgmental examinations of a modest program in its tender years needing all the support it can muster. Evaluation would be negative if it provides fodder to potential critics.

Definition of Evaluation

Literally, evaluation simply means to judge or determine worth of quality. Thus, evaluation contains two elements. First, it includes a judgment as to worth or what is desired. Second, it must also entail measurement of the degree to which the real world matches the judgment of what is desired. Although all of us have seen evaluation projects undertaken as discrete and separate formal efforts, often involving significant budgets, evaluation certainly does not necessarily assume this nature. It need only involve a judgment as to worth and a measure of the degree to which one or more aspects of the real world attain this.

It is important to note that judgment and value is essential to evaluation. This is clearly true by definition of all evaluations no matter how elaborate or complex scientifically.

Within this general definition of evaluation there is a further definitional aspect of evaluation which is germain to this paper and a general understanding of the State of the art in what is commonly termed social program evaluation. This is the distinction between "evaluation" and what Suchman terms "evaluative research." The latter is defined as the "utilization of scientific research methods and techniques for the purpose of making an evaluation."[1] Evaluative research, as thusly defined, is the foundation upon which the current State of the art in formal evaluation has been built. For our purposes, there is one central concept implicit in "evaluative research" as defined by Suchman which needs to be considered. This relates to the scientific method and its concern with establishing empirical relationships between cause and effect. Thus, "evaluative research" extends our initial definition of evaluation by going beyond the search to define worth or value and measure the state to which that value has been obtained in the real world. Evaluative research seeks also to attribute the state of reality to particular causes or stimuli such as individual social programs or projects. For example, if we judge that it is worthwhile to have all mentally retarded adults gainfully employed, we can collect data on the degree to which this condition holds, thus having conducted an evaluation. "Evaluative Research" would go further in that it would build a set of hypotheses as to factors related to gainful employment of the mentally retarded and collect empirical evidence to establish or disprove such an hypothesis. A favorite hypothesis in evaluative research is that a particular program or project has a positive effect on goal attainment. "Evaluative research" must necessarily probe at the question of how the world would be with and without the stimuli or causes with which it is concerned. For example, if a set of training programs in a particular state have as a goal increasing the competitive employment of participants, evaluative research requires that attainment of competitive employment as the result of the program be carefully defined and measured and compared with a selected control group to insure that any changes in competitive employment can be actually attributed to the sheltered workshop experience and not to other factors such as chance, selection procedures, maturation due to lapse of time, or job availability due to shifts in the job market.

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[1] Edward A. Suchman, Evaluative Research, 1967, p. 7.

The business of establishing cause and effect often gets into use of control groups. Suchman identifies three main conditions of "evaluative research": (1) sampling equivalent experimental and control groups; (2) isolation and control of the stimulus; and (3) definition and measurement of criteria of effect."[2] Much of the technical literature on evaluative research relates to the enormously complex subject of applying the rigors of the scientific method to the evaluation of social programs.

The theme of this paper is that on the limited budgets available to State DD programs, evaluative research is usually not practical. However, what I would term "practical evaluation" can be both feasible and useful. "Practical evaluation" can be thought of as having the following characteristics:

(1) Seeks to obtain information for use by State DD Councils and agencies which is directly relevant to the planning and operation of State DD programs.

(2) The presence or absence of such data has the potential for making a significant difference in the State DD programs' effectiveness.

(3) Has as a basis an explicitly stated judgment as to the worth or value of a real world condition.

(4) Involves data collection related to value statements.

(5) Is feasible with given budget constraints.

Note that the definition of "practical evaluation" does not include the task of systematically establishing cause and effect relationships. This by no means downs the value of practical evaluation, since the external judgments of executives can and, of course, always are substituted for scientific proof in its absence. Practical evaluation can offer the very valuable contribution of:

(a) Impetus toward greater discipline in defining program goals and,

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[2] Ibid., pg. 102.

(b) The obtainment of the information on the State of the world as it relates to program goals and overall program planning.

Types of Evaluation

To give a perspective to our practical discussion, note that there are various types of evaluation defined in the growing body of literature on evaluation.

Suchman offers five categories of evaluation.[3]

(1) ***Effort*** – This type of evaluation is concerned with the quantity and quality of activity that takes place and is not directly concerned with output. For example, one of the concerns of a Federally-sponsored evaluation of state DD programs was the degree to which the State Advisory Councils and designated state agencies had achieved an impact on pre-existing Federal and state programs in terms of the increased commitment of these programs to the DD population. Data was sought on increases in the percentage of budget of the respective programs expended on the DD population.[4]

(2) ***Performance*** – This type of evaluation is concerned with analysis of the results of the effort under consideration rather than with the effort itself. If the study mentioned above had sought to measure the degree to which the vocational functioning of members of the DD population had improved as a result of involving the State Vocational Rehabilitation agency in a DD planning process, it could fall into the performance category of evaluations.

(3) ***Adequacy of Performance*** – This type of evaluation seeks to determine the degree to which services provided throughout a State are adequate to meet the overall needs of the DD population. In short, it seeks to determine the degree to which all needs have been met.

(4) ***Efficiency*** – This type of evaluation is concerned with identifying means to continue on-going programs in ways that use less resources and still provide the same results. Some of the debate surrounding community care vs. institutional care for a portion of the DD population has this character, although many of us would agree that a more important issue in this debate is the "normalization" concept.

(5) ***Process*** – This type of evaluation is concerned with identifying what there is about successful programs that makes them work and conversely what there is about unsuccessful programs that leads to failure. Lessons can then be applied to project improvement. An example might include an evaluation of the nature of community involvement in the planning of projects for residential facilities for the DD population and how various processes have contributed to overall community support of residential facilities. On a national level, an evaluation study of State DD programs being conducted at Brandeis is heavily concerned with organizational characteristics of State DD programs and how these characteristics influence program operations.[5]

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[3] Ibid., p. 61.

[4] Larson, Corrine W., Wiechers, James E. *Survey of Operation of the Developmental Disabilities Services and Facilities Construction Act of 1970 (P.L.-91-517) in States,* October 31, 1972.

[5] Binstock, R. *The Roles and Functions of State Planning Systems: Preliminary Report on a Nationwide Survey of the Developmental Disabilities Program*, March, 1972.

Other types of evaluation also exist and are important, including especially the evaluation of assumptions.

All of the types of evaluations listed are relevant to State DD programs and deserve consideration in establishing state evaluation activities. Given limited resources, evaluations of effort and adequacy of performance seem the most useful and feasible at the state level. Of course, evaluation of the performance of each district project funded with DD monies should be built into the project design.

Uses of Evaluation

The overall purpose of evaluation is to increase the effectiveness of programs and administration.

Suchman describes the components of program administration as including research, planning, demonstration and operation.[6] Evaluation is relevant to each of these administrative components. Of particular interest to State DD Councils and designated state agencies are the uses of evaluation for program planning and operation. Planning seems to require the evaluation of three basic components: needs, resources, and community attitudes.[7]

It is useful to think of state level planning for the developmentally disabled as consisting of, among others:

(1) Identification of the existing service and facility inventory and current needs.

(2) Identification of the contribution of pre-existing state and Federal Programs to the DD population, and

(3) Allocation of resources and activities to change 1 and 2.

The formal state plan requirement under P.L. 91-517 also requires that the effectiveness of state programs under the plan be assessed.

How can "practical evaluation" help? Note that in relation to point 1, since needs are always relative, judgment is necessary to define a frame of reference against which existing services can be compared to define current need. Thus, the measurement of current need comprises an "evaluation" of existing or current needs. In relation to point 2, thinking about the ideal role of pre-existing State/Federal programs and obtaining data on the degree to which that role is fulfilled relates to practical evaluation. In relation to point 3, the development of ideas and alternative proposals for the allocation of resources offers the potential for using practical evaluation to test key assumptions in advance of allocation and/or the measurement of the degree to which desired change has been brought about by the allocation decisions made. Such evaluations could provide a partial rationale for continuing some projects and readjusting assumptions in future allocation decisions.

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[6] Suchman, p. 134.

[7] George, James "Planning and Evaluation of Health Programs" in *Administration of Community Health Services.* International City Managers' Association, Chicago 1961, p. 133.

Can Evaluation be a Threat?

Some program administrators and sponsors fear evaluation. They are committed to their overall programs, know that funding is inadequate to meet total needs, and know that a positive community attitude towards programs is essential and often obtained only after long cultivation. They also know that hardly any program is perfect and may fear that evaluation results might be used against the program with resultant loss of funding and/or community support.

These are real concerns and from a practical perspective, cannot be ignored. Program administrators will have to weigh these risks against the positive advantages of evaluative data in its support of (a) more informed and more effective program decisions, and (b) the positive use that can be made of evaluative data or program accomplishments. The risks (as well as the advantages) of practical evaluation compared to evaluative research are smaller in the sense that "practical evaluation" does not pretend to offer valid measures of overall program worth both because it is smaller in scope and not "scientifically based." Thus, no one can objectively argue that evaluation results per se represent an independent judgment of program worth. On the other hand, practical evaluations, since they require judgments for interpretation, run the risk of being used inappropriately.

WHAT TO EVALUATE?

The state plan under P.L. 91-517 requires that states develop methods to assess the effectiveness of state programs under the plan. Thus, project performance evaluation must be undertaken. What else? It is recommended that the answer to this question be provided by state level DD planning in the spirit of practical planning by answering the question of what information is judged to be of value in the ongoing process of planning state programs.

Included in this section are some areas for consideration. Note that evaluation in these areas will involve resource considerations. This section concentrates mainly on the question of useful areas for evaluation, while Section 3 presents some ideas for undertaking evaluation studies on limited budgets.

Degree of Unmet Need

This type of evaluation was referred to previously as ' adequacy of performance." It is essentially concerned with developing judgments as to the needs of the various developmentally disabled and collecting data on a periodic or ongoing basis in relation to defined needs. It is most usefully conducted on a regional or community basis since project grants are usually awarded on this basis in relation to defined needs. It is most usefully conducted on a regional or community basis since project grants are usually awarded on this basis in relation to defined needs and service capacity for some (but not all) services are provided on a substate basis. Such evaluations serve to allow for a finer grained, more effective allocation of resources than statewide estimates allow.

Testing of Assumptions

With data as scarce as it is, planning usually involves making judgments based upon incomplete information, necessitating assumptions. Rarely are assumptions made without at least some information as a foundation. However, it is also rare that no uncertainty remains. In some cases the collection of data to evaluate assumptions will be extremely valuable to state planning. Consider the hypotehtical case of a state which after reviewing available aggregate state data on community service capacity judged community day care facilities to be the greatest unmet service resource. The state then decided to allocate its total service budget to fund the creation of day care facilities throughout the state by soliciting grant proposals from state regions at a funding level proportional to the regional population density. This state could wisely consider testing the assumptions prior to program initiation that (1) day care for the DD population was indeed the highest need and (2) the degree of unmet need was distributed on a basis of population density.

Service Gaps

The term "Degree of Unmet Need' refers to an aggregate counting of the service needs of the developmentally disabled on a substate basis. The term "Service Gaps" as used here is a more qualitative attempt to identify for those service needs where a range of services is required, if there is a particular weak link or shortage of an individual type of service that prevents related services from working in concert to achieve a desired objective. This condition can prevail even in cases where all types of services are at lower levels than desired. For example, first, a community might have the general capacity in terms of training, and residence arrangements to furnish long term care as an alternative to institutional placement but lack guardianship and protective service capacity. Thus, though lack of this single set of services the other community services might not serve as many individuals as aggregate measures of capacity as resource expenditures would suggest. As a second example, sheltered work shop slots and available jobs might exceed the availability of transportation services thus making those services relevant to fewer individuals.

Where this type of situation exists, its identification tends to have high payoff in terms of allocating limited additional resources. Evaluation of service gaps usually requires having involvement of local communities. It also requires as a foundation a reasonably defined model of the range of services relevant to a particular type of problem.

Contribution of "General" Programs[8]

This type of evaluation is related to the intent of the State DD program to coordinate and assist in the planning of how the generic service programs might effectively meet the needs of the DD population. It requires the development of explicit definitions of the type and degree of services each generic program can usefully provide. The collection of data on the degree to which these specifications are met in practice then follows.

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[8] By "generic" program is meant a pre-existing federal or state program which tends to offer one particular type of specialized service such as vocational rehabilitation, public assistance, social services, etc. Nine specific programs are referenced in the law and regulations.

Project Impact

This type of evaluation is concerned with evaluating the success of individual projects, for example those funded by state DD programs, in obtaining their objectives. For example a project to create a sheltered workshop with the goal of serving a specified number of individuals and preparing them for competitive employment would be avaluated in relation to its attainment of these goals. The results of project evaluation are useful in a variety of ways including project management, decisions regarding continued project funding, and replication of the project in other areas.

How to Evaluate?

Books have been written on this subject and some useful ones are referenced in the Bibliography. A definitive treatment here is neither possible nor desirable.

However, it is useful to consider practical evaluation as consisting of the following steps:

1. Explicit statement of program goals and/or models (idealized statements as to desired states of the real world).
2. Explicit identification of assumptions the validity of which seems key to overall program success.
3. Determination of the information which would be of highest value in planning a state program as its individual elements so as to insure maximum program impact.
4. Selection of information needs judged to be of the highest priority and obtainable within budget.
5. Design of evaluation efforts to collect needed data.
6. Conduct or sponsor data collection.
7. Analyze and use results in the state planning process.

Financing Evaluation

Much "practical" as opposed to evaluative research can be done at little or no cost. For example, some data can be furnished by planning staffs of various agencies and other information obtained by a phone call. The value of information is not formally related to the expense or difficulty in obtaining it. However, as evaluation studies become more formal and scientific, their expense mounts rapidly. Following are a few suggestions related to decisions as to how much funding to allocate to evaluation, ideas on evaluations on a low budget or "shoestring," and information related to obtaining additional evaluation resources outside state developmental disabilities programs.

How Much to Spend

Every State DD program makes a decision as to how much effort and funding to allocate to evaluation. Ideally, the results of vigorous evaluations of the full scope of statewide activities both by the generic agencies and the state DD agency would be desirable. Practically speaking, however, state DD resources are quite limited to the extent that a major scale scientifically vigorous evaluation could consume all or a major portion of the State DD budget. Two guidelines are offered. First, it is suggested that the state DD planning effort not dismiss evaluation as impractical under the circumstances but think very hard about the objectives, assumptions, and data it is using to plan state DD programs. An examination for the true degree of knowledge and uncertainty behind program assumptions, then should follow the question of the impact on the states' program. This discussion will provide insight into the value of obtaining additional information and provide a basis for considering the amount of resources it is worth expending to improve knowledge and judgment. Sometimes, specific questions generated in this manner can be answered at little or no cost. This procedure provides the only practical means for wisely allocating resources to evaluation.

Second, as a much less meaningful rule of thumb, many Federal programs have a 1 percent (maximum) set aside for evaluation. This formula could be mechnically transferred to the State level by combining the program budgets for the state DD program and the non-generic programs specified in the DD Act. The percentage of the clients served by the programs which are developmentally disabled could then be estimated along with a proration of the total budget allocable on a per capita basis to the developmentally disabled. One percent of the result would provide a crude indicator of a statewide evaluation resource commitment that matches the Federal convention.

Evaluation On a "Shoe String"

The Developmental Disabilities (DD) program provides only modest funding for the programs of each State. The conduct of expensive evaluations out of the programs budget is not wise. In this sense the state DD programs face conducting evaluation on a "shoestring"! Following are a few ideas which might be useful to consider in this situation.

Consider the first step of evaluation presented earlier: "definition of objectives." Given a limited evaluation budget and a judgment on the part of the state level DD planning group that formal evaluations are too expensive on a major scale, it is worthwhile giving special attention to consideration of investing a portion of limited resources to the area of defining program objectives more explicitly. Not only is such a step inseparable from all formal evaluation that might follow, it is fundamentally related to sound program design and management. It is my personal bias that if resources allow nothing else to be done beyond this step, that it is a most worthwhile undertaking in its own right. It will pay handsome dividends.

Second, consider decentralizing as much as possible the task of evaluating projects funded by the state DD program. An explicit statement of program objectives as discussed in the previous paragraph will help here. The state agency can then require the development of applications or plans for each funded project which specify project objectives in measurable terms and delineate services to be provided. Applications or plans can be required to detail the measurement techniques and procedures to be used to measure project input in relation to project goals. The success of this strategy would be facilitated if a capability within the state to offer technical assistance to project planners and applicants could be identified and made available.

A third idea for "shoestring" evaluation is to expend resources on obtaining a "view of the world" which can be used as basic data for the continuous business of state program planning. This would entail essentially collecting data on how many people in the State are developmentally disabled and need services, the degree to which they are served, and where dollars expended both by the generic programs and the DD program. This data input can be obtained by formal data collection surveys or simply by paying one or more professionals full or part time to look at and report on as systematic and comprehensive a basis as possible what is actually going on.

A fourth idea for low budget evaluation is to identify and select "keystone" issues on which information, if obtained would be of direct, major, and predictable falue to state level DD program planning. In a sense this could be considered as program planning hypothesis testing. For example, a state might infer from aggregate state level statistics that there is a general undercapacity in the state of day care services for the developmentally disabled and tentatively conclude that bridging this gap should assume statewide priority for use of DD funds, and prepare to solicit proposals from each region in the state in relation to this priority. Prior to launching its program, the state might find it useful to evaluate the implicit hypothesis that a statewide shortage of day care services implies a consistent shortage of such services for all regions and thus constitutes an appropriate *statewide* priority. Evaluative data could show that while a valid statewide priority, adequate services might already be in place in some regions.

Fifth, consistent with the shoestring philosophy, a systematic qualitative survey of ideas and attitudes might be considered. It is often a longer distance than we realize, from the seat of government to those immediately faced with social problems. Sometimes our impressions are based on only a few observations and are not representative. Simple systematic surveys of parents and professionals who are directly facing the social problem to glean attitudes and ideas can yield dividends in relation to the costs entailed. Also, new ideas can be tested using this as a "sounding board."

Sixth, some useful evaluation findings can be gleaned from evaluation studies sponsored by others. Reports on the results of such evaluations can be obtained from the sponsoring agencies. The author knows of three national level evaluations ongoing or completed related to the DD program.[9] Copies of available reports on these studies can be obtained from the Division of Developmental Disabilities, Rehabilitation Services Administration, Department of Health, Education, and Welfare.

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[9] See References 4 and 5. The first study is complete. The second is ongoing. Also, Florida State University is undertaking a study of selected state DD programs; Project Director Kingsley Ross. No reports are yet available on this study.

Finally, state DD programs can seek to obtain additional funds for evaluation purposes. There are a number of potential sources outside of state DD programs which potentially offer funds to finance state level DD evaluation programs. One is the Federal level DD office which has funds including a set-aside for "projects of national significance." This pool of funds, as well as funds from grant giving foundations, is open to consideration of the funding state evaluation projects, especially if the projects to be evaluated are of national interest. Two categories of projects of broad Federal interest are: first, those which relate to the evaluation of potentially meritorious projects dealing with alternatives to institutional care, and second, projects which relate to promoting the degree of independence of the individuals involved. Obviously, these example areas represent broad categories into which many state projects would fall. A major and most important potential source of evaluation funds and resources is that in the hands of the "generic" service programs such as vocational education, vocational rehabilitation, etc. Each of these programs has an obligation to serve the DD population. There is no end to the cooperative evaluation efforts which could be jointly sponsored with the generic agencies or instigated by the DD program and financed or conducted by the generic agencies. Such programs could range from (a) evaluating the degree to which a generic program actually serves the DD population, (b) evaluating the special needs of the DD population in relation to services offered by the generic program, to (c) evaluation of special programs of the generic agency aimed at the DD population. Information on these areas is clearly at the heart of state level DD planning.

Potential Additional Federal Funds

Appropriations for federal programs often (but not always) contain provision for the financing of evaluations related to that program. Note that a stipulation on the use of funds is that evaluations funded by of an "evaluative research" character rather than of a "practical evaluation" nature as discussed in this paper.

The HEW Assistant Secretary for Planning and Evaluation has responsibility for developing an evaluation plan covering their areas of program responsibility. State Developmental Disabilities agencies can, working with "generic" programs at the state level (or directly in the case of the Developmental Disabilities program), submit evaluation proposals through the HEW Regional Director at the respective HEW regional offices as a means of applying for evaluation project funding.

Table I suggests the magnitude of evaluation funds potentially available in the future by program using fiscal 1972 as a frame of reference.

Table I

HEW EVALUATION FUNDS
Fiscal Year 1972

SOCIAL AND REHABILITATION SERVICE	**483,537**
Vocational Rehabilitation	250,000
Aging	154,250
Youth Development and Delinquency Prevention	25,000
Developmental Disabilities	54,287
OFFICE OF EDUCATION	**2,456,250**
Elementary and Secondary Education	956,250
Education for the Handicapped	137,500
Higher Education	225,000
Education professions Development	250,000
Bureau of Libraries and Educational Technology	100,000
Research and Development/Training	562,500
Vocational and Adult Education	225,000
HEALTH SERVICES AND MENTAL HEALTH ADMINISTRATION	**3,843,250**
Bureau of Community and Environment Management	14,750
Center for Disease Control	122,000
Community Health Service	749,250
Federal Health Programs Service	114,000
Health Facilities Construction Service	590,250
Indian Health Service	191,250
Maternal and Child Health Service	299,000
National Center for Family Planning Services	193,750
National Center for Health Services R&D	155,250
National Institute of Mental Health	1,130,000
National Institute of Occupational Safety & Health	66,250
Regional Medical Program Service	217,500
NATIONAL INSTITUTES OF HEALTH	**2,327,037**
Institutes	1,000,000
Bureau of Health Manpower Education	1,327,037
	9,110,074

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The single most authorative work on social program evaluation is as follows. It is readable by laymen:

Suchman, Edward A., *Evaluative Research, Principles and Practice in Public Service and Social Action Programs* Russell Sage Foundation; New York, 1967

The best overview of the evaluation efforts conducted by the Federal government and the state of art and point of view they reflect is presented in:

Joseph S. Wholey, et. al. *Federal Evaluation Policy.* The Urban Institute, Washington, D.C., 1970

Individual Data, Program Evaluation and Longitudinal Research[1]

R. K. Eyman, George Tarjan, C. V. Keeran

INTRODUCTION

This topic has historically represented a most neglected endeavor, particularly in the fields of mental retardation and mental health. Despite the current national emphasis on the words "evaluation" and "accountability" in such fields as Developmental Disabilities, Education, Mental Health, etc., the fact remains that practically no systematic data are available on the recipients of service in these areas. It is usually understood that the ultimate objective of any evaluation is to determine the magnitude of beneficial effect produced in individuals by a complex array of services. It should be helpful then to review here some of the problems which require solutions before any future optimism on this topic is warranted. Relevant to the problem of developmental disabilities, we will focus specifically on one of the better defined disabilities, mental retardation.

HISTORICAL PROBLEMS

In the late 1800's, many professionals envisioned residential institutions for the retarded as a "cure for retardation" and an "attainment of normality" for affected children fortunate enough to be admitted. Before long, however, as the institutions grew in size and waiting lists for admission developed, it became clear that the original optimism had not been warranted.

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[1] This investigation was supported by U.S. Department of Health, Education, and Welfare grant No. HD-04612 to the Neuropsychiatric Institute, UCLA; grant nos MH-08667, HD-05540, 54-0-71020/9-01 (SRS/RSA/DDD), and FR-05632 to Pacific State Hospital. Computing assistance was obtained from the Health Sciences Computing Facility, UCLA, sponsored by NIH grant No. FR-3.

Eyman, Department of Psychiatry, UCLA, and the Pacific-Neuropsychiatric Institute Research Program at Pacific State Hospital; Tarjan, Department of Psychiatry and the Mental Retardation Program, Neuropsychiatric Institute, UCLA; and Keeran, Mental Retardation Program, Neuropsychiatric Institute, UCLA.

As late as 1950, neither the overall goals of the institutions nor those of their program components were clearly defined, and attempts at program evaluation were practically nonexistent. Not even basic demographic or epidemiologic information was available either on newly admitted patients or those in residence. Their development, their adjustment, or lack of it went unmonitored. There were no estimates on the probabilities of such critical events as death or release from the institution. As later documented, discharges were few and turnover rates were low. Alternatives for institutional care went largely unexplored. As long as the retarded were housed out of sight and out of mind, they were also kept out of social conscience.

The present scene probably can be described best by emphasizing its highly transitional and changing nature. The retarded are cared for in a variety of settings from home to residential institutions. The involvement of the private sector is on the rise and in most situations at least some special services are available. On the other hand, the stability of the old systems has not been replaced by similar experiences in the new ones. Consequently there should be some concern over the quality of care given in the mushrooming community programs, some of which are operated with profit as a motive.

The AAMD (the American Association for Mental Deficiency) appointed an Ad Hoc Committee in 1968 to investigate the use of data banks in mental retardation. A national questionnaire survey was conducted in 1968 and the results were reported the following year (Eyman & Committee$^{(6)}$). A total of 463 questionnaires were mailed to institutions and agencies in the 50 states shown to provide service for the mentally retarded. Two hundred and fourteen (46 percent) were returned of which 129 respondents (28 percent) reported that some data were available. However, only 24 of the 129 respondents (20 percent) were collecting longitudinal data including some developmental data on the registered clients (data pertained to special research projects or to institutionalized mentally retarded individuals). Lacking a more intensive investigation of data systems reported to be in existence across the nation, it is difficult to *empirically* evaluate the current state of the art.

One might argue that we have just about developed some systematic information and capacity to monitor the retarded in public institutions (Mental Retardation Source Book$^{(14)}$). But there can be no debate over the fact that the proportion residing in institutions is declining, or that we know little about those who leave, or those who do not even enter. We have practically no information concerning their way of life or adjustment in the communities. In addition, statistical information collected by states for the purpose of an annual report or legislative budget hearing has seldom been used for the purpose of understanding or analyzing either treatment procedures or the forces associated with the prevention or control of problems relating to the developmentally disabled.

Dispersed programs, however, require stronger emphasis on coordination, on standards with rigid enforcement, and on continuous quality control. These goals cannot be accomplished without systematic evaluation of both large and small programs. Such assessments are impossible without an adequate system of follow-up. Current knowledge in epidemiology and in computer science is more than adequate for the maintenance of individual and population data with full attention to privacy and confidentiality. Without such monitoring and quality control, it is entirely possible that large segments of community care should prove as disappointing as institutional care.

Current failures regarding data collection and evaluation systems can largely be laid to political, logistical, or jurisdictional problems rather than technical ones. An example of the latter is that although numerous states spend millions of dollars on the delivery of services, they are unwilling to spend money to investigate the efficiency and effectiveness of their programs (Developmental Disabilities Division (DDD) Biometric Conference sponsored in 1969). States still differ greatly from one another with most wishing to remain as autonomous as possible. It is therefore likely that in the near future any nationwide model of data collection and analysis will have to be implemented with careful attention to local customs and priorities. Such variability, though troublesome, can provide opportunities for comparisons and experiments.

CONCEPTUAL ISSUES

Assuming the commitment for data collection and evaluation is realized, it is then necessary to establish some ***ground rules*** for undertaking the task. For example, there is a tendency among some agencies to think of evaluation exclusively in "Program Planning and Budgeting" (PPB) terms in which the dominant indicator of program success is fiscal efficiency.

It is not unusual in such instances to focus on a variety of data, ranging from staffing patterns and accounts of space utilization, but totally neglect data on individuals relating to the impact of a program on the child or adult client presumably receiving a service.

Given the current provisions under the 1970 Developmental Disability Services Act (DDSA), there is still little evidence of activity on the evaluation of a program or service in terms of its impact on the individual client. For the purpose of discussion, we will ***propose a model*** needed if this task is to be accomplished. The specific model suggested is based on data related to individuals and stipulates not only that the ***placement*** of the client in a living plan or the provision of services is important but also that the *succession* of placements and services over time is a key factor for the client's development. When we refer to *placements* we are specifying the physical location of the client in a living arrangement. When we refer to *services*, we are referring to the other specific forms of aid. However, placement is regarded as a service, and certain placements infer certain services, so the terms are not really mutually exclusive. When we refer to *status* of a client however, we are concerned with all information available on the current degree of well-being of the individual. Placements and services should be provided as they become appropriate and be discontinued when no longer appropriate. While this may seem to be "common sense" we question whether there has been sufficient systematic investigation of the effects of status changes on placements and services.

The first element required for such systematic investigation is a ***historical file*** recording the starting and terminating dates for placement and service changes. The principle of such a file is simple, but it soon becomes awkward to handle over a period of time unless there are well thought out methods utilized to keep it current and correct. Knowledge of the problems of mass data handling and adequate computing equipment is essential. There are also additional problems involved in maintaining records that, at first glance, may appear to be of little relevance to the client's problems or are seen by program administrators as having no immediate managerial use. This latter factor is undoubtedly why most agencies with which we have had contact do not maintain such files.

The typical client census file is a cross sectional one, listing those currently receiving services or on a specified placement. While such a file is useful in assessing the current *activities* of the agency, i.e., how many people are being served, and at what cost, they furnish *no* way of determining what impact the services have on the clients. This can only be done over a period of time by comparing groups of clients receiving different types of services.

To make such comparisons requires the maintenance of at least a minimal amount of information of two types: 1) basic demographic characteristics and 2) developmental data. By basic demographic characteristics we are referring to identification and diagnostic data such as sex, age, ethnic status, IQ or level of retardation (if appropriate), and type of disability, i.e., diagnosis. This information is usually available since it forms the basis of at least an initial estimate of services to be provided.

Of more interest, and therefore inevitably the subject of more debate, is the second type of information, which we will characterize as developmental data. Such data may include information on the clients' physical, behavioral, intellectual, emotional, and educational characteristics, etc. Sets of information of this type collected at consecutive time points enables one to assess progress or regression in development. Depending on the rate of natural change, desirable time limits may vary from very short intervals, i.e., weekly, to much longer one, i.e., yearly. Data collection must continue at all times because without such information on the client's progress, we doubt the value of cost tabulations. From the client's point of view it is highly irrelevant whether a service that does not accomplish its aims costs $1,000.00 or $1.00.

IMPLEMENTATION

The implementation of a regional or national data system must take into account the ***geographical variability*** in sophistication of participating agencies. Practicality demands that one start out with a minimal set of data useful for initial assessment of developmental progress of groups of clients. This set, however, must be standardized within the entire geographical area in which the data are to be used for comparison. Such a geographical area may be limited to a county, state, a nation as a whole, or, ultimately, allow international comparisons.

Such ***standardization*** cannot be limited to developmental data alone, it must include the demographic, placement, and service information as well. With standardization of all of these data, no meaningful comparisons can be made, for example, either between two types of service or between two networks operated in two different geographical localities. Demographic data, developmental status, placement, and services constantly interrelate with one another; the impact of none of these can be assessed without adequate information on all others. Comparisons are meaningless unless measurements are standardized. Demographic data are reasonably well standardized and pose no major problem with the exception of a unique identification number used for interagency tracking. In the latter instance, it appears a scramble of the name, sex, and birth date will offer a possible solution to a standardized identification number which retains the anonymity of the client.

There is substantial experience at hand with ***developmental data*** but mostly limited to institutional settings (Dingman,(3) Dingman, et al.,(5) Eyman & Committee,(6) Eyman, et al.,(8) Eyman, et al.,(10) Foster & Foster,(11) Foster & Nihira,(12) Lohmann, et al.,(13) Mercer, et al.,(16) Nihira,(17) Nihira,(18) Nihira, et al.,(19) O'Connor, et al.,(20) O'Connor, & Hunter,(21) O'Connor, et al.,(22) Taaffe & Hardison,(26) Talkington & Hall,(27) Tarjan, et al.,(30) Tarjan, et al.,(31)). Use of such developmental data collection systems in community programs would require considerable preliminary work in standardization. In fact, this may pose the largest problem for the establishment of a meaningful evaluative data system.

Even if definitions for each bit of information were agreed upon, interrater reliability would have to be determined in a host of agencies. It should be remembered that most of these measurements depend upon judgments of observers and the background and sophistication of these individuals often varies from agency to agency. Furthermore, we also expect that substantial disagreements will develop even around the question of inclusion or exclusion in a set of data of any specified developmental variable. For ***placements*** there is no formal categorization as yet, but on the basis of initial surveys that we have made, it appears that there is remarkable similarity in the types of plans offered, and that it would not be difficult to devise a categorization in which the items would be mutually exclusive within a set.

Services pose a somewhat greater problem. Often the labeling of a service depends more on the characteristic of the agency which provides it than upon the content of the service. Similar procedures, may be called early preschool education in one place and therapeutic day care in another. Fortunately, there already exists a DDS-defined categorization of types of services into 16 primary classes. This set can form an adequate starting point for further development. Inevitably some agencies or states will add other categories or divide certain classes into subunits. In either case, redefinitions and reliability testing will be required to make a total set suitable for comparisons. The Appendix represents a tentative proposal for monitoring demographic, developmental, placement, and service data. As can be seen, the data set appears rather voluminous. This fact brings us to another critical issue.

How much or how little ***to collect*** is of practical, economic, clinical, and scientific relevance. Ideally, one must seek the minimum amount that provides maximal return from the viewpoint of program evaluation. Our experience as well as our theoretical inclinations suggest to us that it is better to obtain reliable information on fewer variables than the other way around. In this context, it is also important that clinical staff responsible for data collection be given some training prior to making their evaluations (Dingman,(3) Dingman et al.,(5) Lohmann et al.,(13) Nihira et al.,(19) O'Connor et al.,(20)).

Only time will provide a definitive answer. We may find that many of our proposed items are superfluous or that additional ones are required to answer some critical questions in evaluation. Items may be eliminated for several reasons; for example, because they prove unreliable when collected in diversified community settings or because they are so highly correlated that one item suffices. On the other hand, it may turn out that more detailed information on medication of on the background of the personnel used as teachers' aides is required before an educational program can be adequately evaluated. We have had both types of experiences, i.e., calling for deletions or additions in our extensive work within institutional settings.

Expecting all areas to adopt 100 percent standardization of data collection within the next *decade* is unlikely, and might even be unrealistic. Differing needs of the various agencies, and the natural desire for autonomy, may interfere with complete standardization.

Why should even minimum standardization be a goal? One answer is that various national funding agencies will justifiably require some data useful for comparative assessment of efficiency. However, we doubt that standardization can be imposed by edict of any federal agency. For example, as long as there is resistance at the local level, such resistance will express itself in the unreliability of the data. Punitive measures in the fiscal realm would only deprive the most needy clients of services because they are apt to be located in the areas having the least scientific sophistication.

Nevertheless, we feel very optimistic about ***voluntary cooperation and collaboration.*** Our experience with institutions associated with WICHE (Western Insterstate Commission for Higher Education) points out this fact. Only one incentive is required: the data and their analyses must be of practical utility to those who participate in the daily labor of its collection. Compliance with this requirement will require some compromises from both federal and state agencies.

Cost data can be collected in parallel, but they involve unique sophistication in economics. For example, the meaning of cost might well be different depending upon whose dollars are involved in the costs. Are they those paid by the consumer directly or through an insurance system; those of a local agency, or a government agency provided through specific granting, or through a formula based allocation? Be this as it may, there is no way to arrive at a correct cost benefit ratio without adequate quantification of benefits. It is this aspect of the equation to which most of this paper has addressed itself.

EXPERIENCES AT PACIFIC STATE HOSPITAL

To place some of the issues described in a practical context, some of the past work done at *Pacific State Hospital* will provide a general description on the use of longitudinal data in research and program evaluation. For example, extensive studies have been conducted on the release, retention and death experiences of individuals admitted to this institution over the past two decades (Dingman &

Eyman,(4) Eyman et al.,(8) Tarjan, et al.,(28) Tarjan et al.,(33) Tarjan, et al.,(34)). A release-return index has been developed for this purpose which represents the average number of days that individuals in specified age, IQ and diagnostic groups have spent on release over a 3- to 4-year follow-up period (Dingman et al.,(4) Tarjan et al.,(33)). Mortality rates were also studied in this context (Tarjan et al.(28)).

It became apparent from early studies (Brown et al.,(2) Sabagh & Windle,(25) Tarjan et al.,(29) Tarjan et al.,(32)) that the involvement of the community sector was on the rise. More recent studies (Tarjan et al.,(33) Tarjan et al.(34)) have documented that time spent on release has generally quadrupled over a 20-year period for most admissions regardless of degree of handicap. The availability of more foster settings, nursing homes, and convalescent hospitals contributed significantly to this trend.

As to mortality, it was found that 6-month and 3-year postadmission death rates were very high for 1949-1951 admissions, decreasing sharply for admissions between 1959-1961, and increasing moderately again for individuals admitted between 1966-1968 (Tarjan et al(34)). This trend was particularly evident among the younger, more profoundly retarded as well as the organically involved individuals. Other data based on mortality of all admissions to Pacific State Hospital Between 1944 and 1962 has suggested that pulmonary diseases continue to be a major cause of death, constituting about 50 percent of all deaths regardless of when admitted (Tarjan et al.(28)). Several studies have documented that low mortality rates could be achieved when intensive monitoring and other programs were instituted (Dingman et al,(5) Dingman et al.,(4) Tarjan et al.,(28) Tarjan et al.,(33)). However, the fact remains that mortality continues to be a major problem and requires study in *both* institutional and community settings as part of *any* evaluation scheme.

Of equal importance, from the viewpoint of later adjustment, assuming survival, is a comparison of basic skills, i.e., ambulatory and toilet skills, between individuals who were placed in special intensive programs for the improvement of self-help skills with those who received only "standard care," i.e., no special program other than general cottage activities. Admissions to Pacific State Hospital between 1962-1964 were followed on a number of adaptive behaviors as part of a larger monitoring program of all residents. It was found that the acquisition of basic skills occurred in only a small proportion of residents under standard care, e.g., 20-30 percent. When such improvements did occur, they took place relatively early after admission. On the other hand, 70-80 percent of the residents who were included in special programs improved in basic skills. A retrospective investigation of these differences showed no more general debilitation for those who did not improve compared with those who did improve (Eyman et al.(8)).

A replication of this study based on more recent admissions and covarying on other resident characteristics at the outset, including age, IQ, diagnosis, initial status, and chronic illnesses further substantiated these results. Finally, Meredith,[2] using an average of eight self-help skills, found moderate but superior developmental gains among institutionalized children assigned to any of the intensive care programs was even more pronounced when cost-benefit figures were compared. The fact that intensive programs *can* improve the outlook of the mentally retarded fortunate enough to be included in them is a sufficient reason for additional study to determine limits and more efficient intervention strategies to reach more individuals.

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[2] J. Meredith, personal communication.

IMPLICATIONS

The discussion up to this point was focused on evaluation of the effectiveness of programs. An equally relevant issue, however, is data on the extent of need for a specified program or service. This issue is complicated, as past experience demonstrates; once additional services are available, the number of individuals seeking those services increases. Such increments may reflect "true" needs, the unavailability of other parallel programs, or dissatisfaction with alternative services.

It is therefore essential to collect data at each entrance point into a global system including those pertaining to early assessment of the individual's needs related to such variables as demographic and developmental factors. Such data is of particular significance at the moment an unusual rise occurs, either in a waiting list or in the number of new entrants into the system. Such increments in incidence or prevalence of need can be related to data available on the epidemiology of mental retardation in a community.

Tarjan et al.(34) have attempted to estimate prevalence and incidence of mental retardation by age and IQ as well as those in need of residential care sometime during their career. These estimates were found to be congruent with data obtained in one California community (Mercer(15)). An overall 1 percent prevalence rate is suggested (in lieu of a 3 percent figure) based on recent evidence of the age-dependency of the label regarding children designated as mildly retarded during their school years and the relatively high mortality of the more profoundly retarded. Although 3 percent of the newborn will be suspected and even diagnosed as mentally retarded sometime during their lives, probably during their school years, it is incorrect to assume that at any given time 3 percent of the population is so identified.

According to Tarjan, et al.:(34)

> The important facts from the viewpoint of prevalence and incidence are: (a) approximately 75 percent of the individuals identified as retarded are adolescents, or younger, with nearly 70 percent being of school age; (b) the initial diagnosis of mental retardation is established in practically 100 percent of the patients before adulthood; and (c) about two-thirds of the individuals diagnosed as retarded lose this label during late adolescence or early adulthood.
>
> Today, the moderately or more severely retarded children with concomitant somatic signs generally come to the attention of pediatricians or family physicians, with only a limited number of mildly retarded children of school age being referred to physicians primarily for this condition. When seen, they are often referred to child psychiatrists. As comprehensive health care more effectively reaches the currently medically underprivileged segments of the population, a broader

> involvement of the medical specialities with this latter group can be expected.

Regarding estimates of institutionalization, a number of studies (Eyman et al.,(7) Eyman et al, (9) Sabagh et al.,(23) Sabagh et al.,(24) Tarjan et al.,(32) Tarjan et al.,(33)) suggest that the probabilities for the most seriously retarded are very high, gradually decreasing for the moderately retarded and becoming very small for the mildly retarded. It is worth noting that the mildly retarded are most likely to be admitted before the age of 6 or during the age period 12-17. The former group will represent young children with Down's syndrome, and the latter group will represent adolescents with functional retardation.

These estimates are related to a prototype community representing a socio-economic status and educational background typical of the general population. In contrast to this type of general population, there are known high risk groups who have been identified in a variety of studies. For example, Alberman and Goldstein(1) have observed:

> Although it is impossible to lay down uniform rules we can give some examples of our recommendations. From the present data it appears that an optimally sized high-risk group, using birth data alone as predictors is about 13 percent of live births. These comprise fifth or laterborn children, those who were delivered abnormally, or those whose condition caused concern after birth. Among these would be about 26 percent of all children with 'unseen' handicaps. In an authority who had been detecting only about 10 percent of such handicaps early—say in the first year—the detection rate could be increased by 50 percent simply by devoting all resources available for this exercise to this high-risk group. Where 30 percent of the handicaps had been detected early, this could be increased by 10 percent by allocating the resources in a ratio of four to one in favour of the high-risk group. (pp. 131-2)

Another study by Werner, Bierman, and French,(35) done on the island of Kauai, resulted in the following conclusions:

> In sum, for each 1,000 live births on Kauai there were an estimated 1,311 pregnancies that had advanced to four weeks gestation, 286 having ended in fetal deaths before 20 weeks gestation and 25 more between 20 weeks and term. The 1,000 live births yielded an estimated 844 surviving children at age two who were free of any observed physical defect requiring special care and who had IQs of at least 85. By age 10, only 660 of these children were functioning adequately in school and had no recognized physical, intellectual, or behavior problem. Thus, during the span of the months of pregnancy and the first decade of life, the reproductive and environmental casualties in this community amounted to about one-half of those conceived and about one-third of the liveborn. (p. 131)

Based on such conclusions, it is evident that ***a complete data system*** must also attempt to eventually include monitoring high risk populations, with the condition that clients would be voluntary recipients of more widely available services. The critical issue is making more diagnostic clinics and services available to these populations so that identification of disabilities and intervention can occur as early as possible.

In conclusion, the issues of data systems for the mentally retarded are complex. When it comes to other disabilities the complexities increase. Whereas there is a reasonably well agreed upon definition for mental retardation, the questions are open as to what proportion of the cerebral palsied or the epileptics fall within the demarcations of the developmentally disabled. In the meantime, it is felt that the quality and effectiveness of existing services can be improved by a greater commitment to longitudinal research and program evaluation based on individual data.

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Appendix

INTRODUCTION

This appendix contains materials and forms which represent a proposal for the implementation of a data collection and tracking system for the developmentally disabled. While intended to be as complete as possible at this time, it is recognized that variation in detail is to be expected so that the needs of local agencies can better be met. At the same time, some standardization of information must be maintained in order that the data is comparable from one geographic area to another. Therefore, the material presented herein is suggested as a minimal set of information that must be collected. Optionally, each area may collect additional information that is not contained in these forms.

The material is divided into four sections:

I. A model of the system of client services and the corresponding data collection scheme for clients receiving services from a state/county system. The client is picked up at intake and evaluated by the agency. The client may change living plans and receive services from the agency until discharge or death.

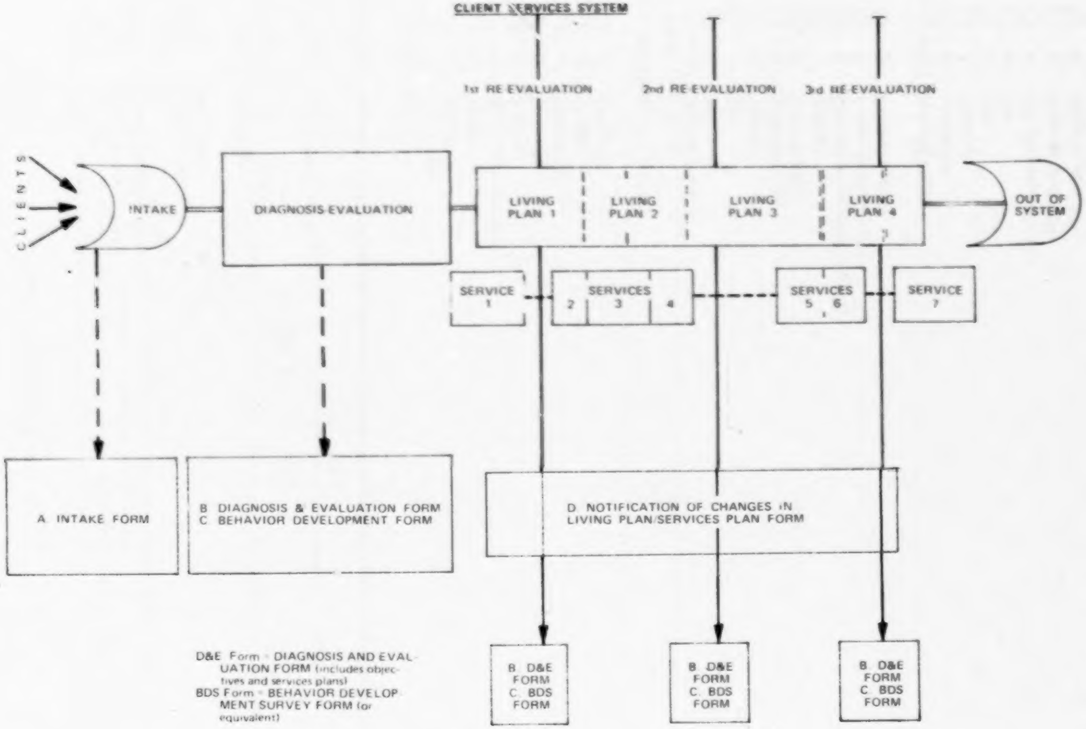
II. The data collection instruments:
   A. Intake: this form is to be completed when contact is initially made with the agency.
   B. Diagnosis & Evaluation: This form is to be completed when diagnosis and evaluation is made and at yearly re-evaluation.
   C. Behavior Development Survey/Adaptive Behavior Forms: Complete this form at initial diagnosis and evaluation as well as at each re-evaluation.
   D. Notification of Changes in Living Plans/Services: this form is to be completed with each change of living plan or service (i.e., initiation of new plan or termination of present plan).

III. An implementation plan, outlining the procedures necessary to convert a state system to a system amendable to data processing.

IV. Reference material: codes for categories and definitions of categories for placements, services and objectives as used in Forms A-D.

I MODEL

CLIENT SERVICES SYSTEM


1st RE-EVALUATION
2nd RE-EVALUATION
3rd RE-EVALUATION
CLIENTS
INTAKE
DIAGNOSIS-EVALUATION
LIVING PLAN 1
LIVING PLAN 2
LIVING PLAN 3
LIVING PLAN 4
OUT OF SYSTEM
SERVICE 1
SERVICES 2 3 4
SERVICES 5 6
SERVICE 7
A. INTAKE FORM
B. DIAGNOSIS & EVALUATION FORM
C. BEHAVIOR DEVELOPMENT FORM
D. NOTIFICATION OF CHANGES IN LIVING PLAN/SERVICES PLAN FORM
B. D&E FORM
C. BDS FORM
B. D&E FORM
C. BDS FORM
B. D&E FORM
C. BDS FORM

D&E Form = DIAGNOSIS AND EVALUATION FORM (includes objectives and services plans)
BDS Form = BEHAVIOR DEVELOPMENT SURVEY FORM (or equivalent)

INTAKE INFORMATION

(1-2) State ____________________

(3-5) Agency ____________________

(6-15) Client's case number ____________________

(16-25) Social Security No. ____________________

(26) Sex ☐ 1 Male ☐ 2 Female

(27-34) Name Code ____________________

(35-40) Birthdate ___/___/___
Mo. Day Yr.

(41-42) Birth State ____________________

(43-48) Date of intake ___/___/___
Mo. Day Yr.

(49-50) Residence County ____________________

---

(51) ETHNIC STATUS
☐ 0 Unknown
☐ 1 White
☐ 2 Black
☐ 3 Spanish-American
☐ 4 Indian
☐ 5 Oriental
☐ 6 Polynesian
☐ 7 Mixed
☐ 8 Other

(52) REFERRAL SOURCE
Name ____________________
Type of Referral Source
☐ 0 Unknown
☐ 1 Self
☐ 2 Family
☐ 3 Friend/clergy
☐ 4 Prvt. Profess.
☐ 5 School
☐ 6 Court/correctional agency
☐ 7 Other (state/county)
☐ 8 Private agency

(53) CLIENT EDUCATION
☐ 0 Unknown
☐ 1 Regular
☐ 2 MR
☐ 3 EH
☐ 4 OE (orthopedic ed.)
☐ 5 Regular and MR
☐ 6 Regular and EH
☐ 7 Regular and OE
☐ 8 Other

(27-74) SIBS LIVING AT HOME RELATIONSHIP TO CLIENT

Birth Years

☐ 1 Sister(s) ____________________
☐ 2 Brother(s) ____________________
☐ 3 Half-sister(s) ____________________
☐ 4 Half-brother(s) ____________________
☐ 5 Stepsister(s) ____________________
☐ 6 Stepbrother(s) ____________________
☐ 7 Adoptive sister(s) ____________________
☐ 8 Adoptive brother(s) ____________________

(27-44) OTHERS LIVING AT HOME RELATIONSHIP TO CLIENT

Birth Years

☐ 1 Aunt ____________________
☐ 2 Uncle ____________________
☐ 3 Grandmother ____________________
☐ 4 Grandfather ____________________
☐ 5 Other ____________________

(45-46) PARENT/GUARDIAN RESIDENTIAL COUNTY

____

(47) GUARDIANSHIP STATUS

☐ 0 Unknown
☐ 1 Bio-parents
☐ 2 Bio-mother only
☐ 3 Bio-father only
☐ 4 Adoptive
☐ 5 Maternal/paternal grandparents
☐ 6 Public guardianship (state/county)
☐ 7 Other

CURRENT PARENTAL FIGURES

Mother	Father
(48-49) Birth year ____________	(60-61) Birth Year ____________
(50-51) EDUCATION	(62-63) EDUCATION
None 1 2 3 4 5 6 7 8 9	None 1 2 3 4 5 6 7 8 9
10 11 12 13 14 15 16 17	10 11 12 13 14 15 16 17
(52-53) RELATIONSHIP	(64-65) RELATIONSHIP
☐ 0 Unknown	☐ 0 Unknown
☐ 1 Biological mother	☐ 1 Biological father
☐ 2 Foster mother	☐ 2 Foster father
☐ 3 Stepmother	☐ 3 Stepfather
☐ 4 Adoptive mother	☐ 4 Adoptive father
☐ 5 Maternal grandmother	☐ 5 Maternal grandfather
☐ 6 Paternal grandmother	☐ 6 Paternal grandfather
☐ 7 Sister	☐ 7 Brother
☐ 8 Aunt	☐ 8 Uncle
☐ 9 Other	☐ 9 Other
☐ 10 None	☐ 10 None

(54) ETHNIC STATUS
☐ 0 Unknown
☐ 1 White
☐ 2 Black
☐ 3 Spanish-American
☐ 4 Indian
☐ 5 Oriental
☐ 6 Polynesian
☐ 7 Mixed
☐ 8 Other

(55-56) OCCUPATION________________
☐ 0 Unknown
☐ 1 Professional/technical
☐ 2 Managerial/proprietor
☐ 3 Sales/Clerical
☐ 4 Craftsman/foreman (plumber, mechanic, carpenter, etc.)
☐ 5 Service manager (policeman, barber, waiter, etc.)
☐ 6 Laborer
☐ 7 Housewife
☐ 8 Student
☐ 9 Retired
☐ 10 Unemployed
☐ 11 Other

(57-59) GROSS YEARLY INCOME
(thousands)________________

(66) ETHNIC STATUS
☐ 0 Unknown
☐ 1 White
☐ 2 Black
☐ 3 Spanish-American
☐ 4 Indian
☐ 5 Oriental
☐ 6 Polynesian
☐ 7 Mixed
☐ 8 Other

(67-68) OCCUPATION________________
☐ 0 Unknown
☐ 1 Professional/technical
☐ 2 Managerial/proprietor
☐ 3 Sales/clerical
☐ 4 Craftsman/foreman (plumber, mechanic, carpenter, etc.)
☐ 5 Service manager (policeman, barber, waiter, etc.)
☐ 6 Laborer
☐ 7 Cares for household
☐ 8 Student
☐ 9 Retired
☐ 10 Unemployed
☐ 11 Other

(69-71) GROSS YEARLY INCOME
(thousands)________________

(72-73) MARITAL STATUS OF CLIENT's parents
☐ 0 Unknown
☐ 1 Parents married and living together
☐ 2 Parents not married and living together
☐ 3 Parents not married and not living together
☐ 4 Parents divorced/neither remarried
☐ 5 Mother remarried
☐ 6 Father remarried
☐ 7 Both remarried
☐ 8 Father deceased—mother remarried
☐ 9 Father deceased—mother not remarried
☐ 10 Mother deceased—father remarried
☐ 11 Mother deceased—father not remarried
☐ 12 Parents separated

PREGNANCY AND PRENATAL HISTORY

(27) GESTATION PERIOD
☐ 0 Unknown
☐ 1 Less than 32 weeks
☐ 2 32-36 weeks
☐ 3 37-40 weeks
☐ 4 Greater than 40 weeks

(28) BIRTHWEIGHT
- ☐ 0 Unknown
- ☐ 1 Less than 1000 gm (less than 2 lbs 3 oz)
- ☐ 2 1001-1500 gm (2 lbs 4 oz - 3 lbs 5 oz)
- ☐ 3 1501-2000 gm (3 lbs 6 oz - 4 lbs 6 oz)
- ☐ 4 2001-2500 gm (4 lbs 7 oz - 5 lbs 8 oz)
- ☐ 5 Greater than 2501 gm (5 lbs 9 oz)

(29) MULTIPLE BIRTH
- ☐ 0 Unknown
- ☐ 1 Yes
- ☐ 2 No

(30) MATERNAL AGE (at birth of child in question)
- ☐ 0 Unknown
- ☐ 1 Less than 15 years
- ☐ 2 15-19 years
- ☐ 3 20-29 years
- ☐ 4 30-34 years
- ☐ 5 35-44 years
- ☐ 6 Greater than 45 years

PROBLEMS IN PREGNANCY	unknown	yes	no
(31) 1st 3 mos.	☐ 0	☐ 1	☐ 2
(32) 2nd 3 mos.	☐ 0	☐ 1	☐ 2
(33) 3rd 3 mos.	☐ 0	☐ 1	☐ 2
(34) At birth	☐ 0	☐ 1	☐ 2

CLIENT'S BIRTH ORDER

(35-36) _______ Live birth order

(37-38) _______ All birth order (including stillborns)

(39-40) _______ All pregnancy order (including miscarriages, abortions, etc.)

BEHAVIOR DEVELOPMENT SURVEY

(1-2) State _______________

(3-5) Agency _______________

(6-15) Client's Case Number _______________

(16-25) Social Security Number _______________

(26) Sex ☐ 1 Male ☐ 2 Female

(27-34) Name Code _______________

(35-40) Birthdate ___/___/___ Mo. Day Yr.

(41-44) Length of time in this facility: ___ ___ Yrs. Mos.

(45-48) Diagnosis (AAMD) _______________

(49-51) IQ _______________

(52-54) SQ _______________

(55) RESIDENT'S ETHNIC STATUS
- ☐ 1 White
- ☐ 2 Black
- ☐ 3 Spanish-American
- ☐ 4 Indian
- ☐ 5 Oriental
- ☐ 6 Polynesian
- ☐ 7 Mixed
- ☐ 8 Other

(56) LEVEL OF FUNCTIONING
☐ 0 Unknown
☐ 1 Normal
☐ 2 Borderline
☐ 3 Mild
☐ 4 Moderate
☐ 5 Severe
☐ 6 Profound

---

(57) AMBULATION (Check only one)
☐ 1 Unable to walk
☐ 2 Walks only with help
☐ 3 Limps or walks unsteadily
☐ 4 Walks with no difficulty

ARM-HAND USE

	Yes 1	No 2
(58) Can catch a ball	☐	☐
(59) Can throw a ball overhand	☐	☐
(60) Is able to lift a cup	☐	☐
(61) Can grasp with thumb and finger	☐	☐

(62) SPEECH (Check only one)
☐ 1 Makes no sounds
☐ 2 Speech is not understandable but makes sounds
☐ 3 Speech very difficult to understand
☐ 4 Speech somewhat difficult to understand
☐ 5 Speech easily understood

(63) VISION with glasses—if used (check only one).
☐ 0 Unknown
☐ 1 No vision at all
☐ 2 Great difficulty in seeing
☐ 3 Some difficulty in seeing
☐ 4 No difficulty in seeing

(64) HEARING with hearing aid--if used (check only one).
☐ 0 Unknown
☐ 1 No hearing at all
☐ 2 Great difficulty in hearing
☐ 3 Some difficulty in hearing
☐ 4 No difficulty in hearing

(65) HISTORY OF SEIZURES (check only one).
☐ 0 Unknown
☐ 1 Seizures observed in last 2 years
☐ 2 History but none observed
☐ 3 None observed and no history

(66) RECEIVING MEDICATION FOR CONTROL OF SEIZURES (check only one)
☐ 1 Yes, uncontrolled
☐ 2 Yes, partially controlled
☐ 3 Yes, completely controlled
☐ 4 No medication required or received

PHYSICAL AID

Does resident use:	Yes 1	No 2
(67) Glasses	☐	☐
(68) Hearing aid	☐	☐
(69) Braces	☐	☐
(70) Walker	☐	☐
(71) Wheel chair	☐	☐
(72) Crutches	☐	☐

(26) TOILET TRAINING (check only one)
- ☐ 1 Is not toilet trained at all
- ☐ 2 Frequently has toilet accidents during the day
- ☐ 3 Occasionally has toilet accidents during the day
- ☐ 4 Never has toilet accidents during the day
- ☐ 5 Never has toilet accidents

(27) BED WETTING (check only one)
- ☐ 1 Usually wets
- ☐ 2 Occasionally wets
- ☐ 3 Never or infrequently wets

CLEANLINESS	Yes 1	No 2
Does resident need help:		
(28) Washing hands and face	☐	☐
(29) Bathing	☐	☐
(30) Brushing teeth	☐	☐

(31) MONEY HANDLING (check only one)
- ☐ 1 Has no idea of the value of money
- ☐ 2 Realizes money has value but does not use money
- ☐ 3 Uses money but does not make change correctly
- ☐ 4 Adds coins of various denominations, up to one dollar
- ☐ 5 Makes change correctly but does not use banking facilities
- ☐ 6 Is able to use banking facilities

(32) PURCHASING (check only one)
- ☐ 1 Does no shopping
- ☐ 2 Does shopping with close supervision
- ☐ 3 Does shopping with slight supervision
- ☐ 4 Makes minor purchases without help (candy, soft drinks, etc.)
- ☐ 5 Buys own clothing accessories
- ☐ 6 Buys all own clothing

(33) DRESSING (check only one)
- ☐ 0 Unknown
- ☐ 1 Does not cooperate in dressing by extending arms or legs
- ☐ 2 Does not dress self but cooperates
- ☐ 3 Partially dresses self, cannot zip or button
- ☐ 4 Partially dresses self, can zip or button
- ☐ 5 Completely dresses self, except tying shoes
- ☐ 6 Completely dresses self

MODE OF CLOTHING	Yes 1	No 2
Does resident:		
(34) Choose properly fitting clothes	☐	☐
(35) Wear torn or unpressed clothing	☐	☐
(36) Rewear dirty or soiled clothing	☐	☐
(37) Wear clashing color combinations	☐	☐
(38) Know the difference between work shoes and dress shoes	☐	☐
(39) Choose different clothing for formal and informal occasions	☐	☐
(40) Choose special clothing for different weather conditions (raincoat, overshoes, etc.)	☐	☐

(41) USE OF TABLE UTENSILS (check only one)
- ☐ 1 Must be fed
- ☐ 2 Feeds self with fingers
- ☐ 3 Feeds self with spoon—considerable spilling
- ☐ 4 Feeds self with spoon—neatly
- ☐ 5 Feeds self with spoon and fork—considerable spilling

☐ 6 Feeds self with spoon and fork—neatly
☐ 7 Uses table knife for cutting or spreading
☐ 8 Uses knife and fork correctly and neatly

(42) EATING IN PUBLIC (check only one)
☐ 1 Does not order at public eating facilities
☐ 2 Orders soft drinks at soda fountains or canteens
☐ 3 Orders simple meals like hamburgers or hot dogs
☐ 4 Orders complete meals in restaurants

(43) ROOM CLEANING (check only one)
☐ 0 Not an assigned task
☐ 1 Does not clean room at all
☐ 2 Cleans room but does not sweep under furniture and does not dust thoroughly
☐ 3 Cleans room well, including sweeping, dusting, and tidying

(44) TABLE CLEARING (check only one)
☐ 0 Not an assigned task
☐ 1 Does not clear table at all
☐ 2 Clears table of unbreakable dishes and silverware
☐ 3 Clears table of breakable dishes and glassware

(45) FOOD PREPARATION (check only one)
☐ 0 Not an assigned task
☐ 1 Does not prepare food at all
☐ 2 Prepares simple foods requiring no mixing or cooking, e.g., making sandwiches, preparing cold cereal, etc.
☐ 3 Mixes and cooks simple food, e.g., frying eggs, making pancakes
☐ 4 "Cooks" an adequate complete meal (may use canned and frozen foods for this purpose)

(46) Vocabulary (check only one)
☐ 1 Is nearly non-verbal
☐ 2 Asks for at least 10 things by their appropriate names
☐ 3 Uses names of familiar objects
☐ 4 Names people or objects when describing pictures
☐ 5 Talks about action when describing pictures

(47) WRITING (check only one)
☐ 1 Cannot write or print any words
☐ 2 Writes or prints own name
☐ 3 Writes or prints 10 words
☐ 4 Writes or prints forty words
☐ 5 Writes short notes and memos
☐ 6 Writes sensible and understandable letters

UNDERSTANDS COMPLEX INSTRUCTIONS	Yes 1	No 2
(48) Understands instructions containing prepositions, e.g., "on," "in," "behind," "under," etc.	☐	☐
(49) Understands instructions referring to the order in which things must be done, e.g., "first do—, then do—."	☐	☐
(50) Understands instructions requiring a decision: "If—, do this, but if not, do—"	☐	☐

UNDERSTANDS TIME, TIME INTERVALS, TIME EQUIVALENTS, ETC.	Yes 1	No 2
(51) Can tell time by clock or watch correctly to the minute	☐	☐
(52) Can associate time on clock with various actions and events	☐	☐

(53) SENSE OF DIRECTION (check only one)
- ☐ 1 Bedfast
- ☐ 2 Gets lost whenever he leaves his own living area
- ☐ 3 Can walk around cottage, ward or home alone
- ☐ 4 Can go around hospital ground or a few blocks from home without getting lost
- ☐ 5 Can go a few blocks from hospital to school ground, or several blocks from home without getting lost

(54) RESPONSIBILITY (check only one)
- ☐ 1 Not given responsibility; is unable to carry out responsibility at all
- ☐ 2 Unreliable—makes little effort to carry out responsibility; one is uncertain that the assigned act will be performed
- ☐ 3 Usually dependable—makes an effort to carry out responsibility; one can be reasonably certain that the assigned act will be performed
- ☐ 4 Very conscientious and assumes much responsibility—makes a special effort, the assigned act will always be performed

(55) INITIATIVE (check only one)
- ☐ 1 Will not engage in assigned activities, e.g., putting away toys, etc.
- ☐ 2 Will engage in activities only if assigned or directed
- ☐ 3 Asks if there is something for him to do or explores surroundings, e.g., home, yard, etc.
- ☐ 4 Initiates most of his own activities, e.g., tasks, games, etc.

(56) WORK FITNESS (check only one)
- ☐ 1 Can perform no work at all
- ☐ 2 Can perform simple work, e.g., simple gardening, mopping floors, emptying trash, etc.
- ☐ 3 Can perform a job requiring use of tools or machinery, e.g., shop work, sewing

(57) INTERACTION WITH OTHERS (check only one)
- ☐ 1 Is completely unresponsive to others in a socially acceptable manner
- ☐ 2 Plays with others imitatively with little interaction
- ☐ 3 Plays with others for at least short periods of time, e.g., showing or offering toys, clothing or objects
- ☐ 4 Plays cooperatively or competitively with others in group games

MALADAPTIVE BEHAVIOR

	Frequently 1	Occasionally 2	Never 3
(58) Threatens or does physical violence to others	☐	☐	☐
(59) Damages own or other's property	☐	☐	☐
(60) Disrupts other's activities	☐	☐	☐
(61) Uses profane or hostile language	☐	☐	☐
(62) Is rebellious, e.g., ignores regulations, resists following instructions	☐	☐	☐
(63) Runs away or attempts to run away	☐	☐	☐
(64) Is untrustworthy, e.g., takes other's property, lies or cheats	☐	☐	☐

(65) Is withdrawn, e.g., seems difficult to reach or contact	☐	☐	☐
(66) Displays stereotyped behavior, e.g., rocks body back and forth, has hands in motion	☐	☐	☐
(67) Removes or tears off own clothing	☐	☐	☐
(68) Does physical violence to self	☐	☐	☐
(69) Is hyperactive, e.g., will not sit still for any length of time	☐	☐	☐
(70) Displays heterosexual behavior that is socially unacceptable	☐	☐	☐
(71) Displays homosexual behavior	☐	☐	☐
(72) Displays other unacceptable sexual behavior, e.g., masturbates, exposes self	☐	☐	☐
(73) Requires seclusion	☐	☐	☐
(74) Requires restraint	☐	☐	☐

(75) CURRENT MEDICATION	Yes 1	No 2
Is resident receiving any regular medication (e.g., pills, capsules, liquids, injections; including such things as vitamins, birth control pills, etc.)?	☐	☐

If yes what is the medication(s) and its purpose?

Medication	Purpose

Your name: ____________

Position: ____________

Date: ____________

DIAGNOSIS AND EVALUATION

(1-2) State ____________

(3-5) Agency ____________

(6-15) Client's Case Number ____________

(16-25) Social Security Number ____________

(26) Sex ☐ 1 Male ☐ 2 Female

(27-34) Name Code ____________

(35-40) Birthdate __/__/__ Mo. Day Yr.

(41) Type of Evaluation
- ☐ 1 Initial evaluation
- ☐ 2 Re-evaluation

(42-47) Date of Evaluation Summary __/__/__ Mo. Day Yr.

Psychological

(48) TYPE OF IQ TEST
- ☐ 0 Unknown
- ☐ 1 WAIS, WISC, or WB
- ☐ 2 Stanford-Binet
- ☐ 3 Peabody
- ☐ 4 Cattell
- ☐ 5 Other

(49-50) Date of Test __/__/__ Mo. Day Yr.

(51-53) Score ____________

(54) TYPE OF IQ TEST
☐0 Unknown
☐1 WAIS, WISC, or WB
☐2 Stanford-Binet
☐3 Peabody
☐4 Cattell
☐5 Other

(55-56) Date of Test ___/___/___
Mo. Day Yr.
(57-59) Score __ ________________

(60) TYPE OF SQ TEST
☐0 Unknown
☐1 Vineland
☐2 Other

(61-62) Date of Test ___/___/___
Mo. Day Yr.
(63-65) Score ________________

(66) TYPE OF SQ TEST
☐0 Unknown
☐1 Vineland
☐2 Other

(67-68) Date of Test ___/___/___
Mo. Day Yr.
(69-71) Score ________________

DIAGNOSIS AND DISABILITY

(27) MR SEVERITY
☐ 0 Unknown
☐ 1 Normal
☐ 2 Borderline
☐ 3 Mild
☐ 4 Moderate
☐ 5 Severe
☐ 6 Profound

(28) EPI SEVERITY
☐ 0 Unknown
☐ 1 Mild
☐ 2 Moderate
☐ 3 Severe

(29) CP SEVERITY
☐ 0 Unknown
☐ 1 Mild
☐ 2 Moderate
☐ 3 Severe

(30-40) DIAGNOSIS AAMD CLASSIFICATION PRIMARY CLASS
____

Supplementary Term Listing
____Genetic component
____Secondary cranial
____Special senses
____Convulsive disorder
____Psychiatric impairment
Motor Dysfunction
____Type
____Location
____Severity

OTHER DIAGNOSIS ICD CLASSIFICATION
(44-50) CP ________________
(51-57) EPI ________________
(58-64) Others________________
____

(41) SEIZURE FREQUENCY
☐ 0 Unknown
☐ 1 Less than 1 seizure/yr
☐ 2 1-6 seizures/yr
☐ 3 7-12 seizures/yr
☐ 4 13/yr – daily
☐ 5 More than 1 seizure/day

(42) TYPE OF MOTOR DYSFUNCTION
☐ 0 Unknown
☐ 1 No motor dysfunction
☐ 2 Motor dysfunction not specified
☐ 3 Ataxia
☐ 4 Hypotonia
☐ 5 Choreoathetosis
☐ 6 Dystonia (tension CP)
☐ 7 Rigidity
☐ 8 Tremors
☐ 9 Spasticity
☐ 10 Mixed

(43) LOCATION OF MOTOR DYSFUNCTION
☐ 0 Unknown
☐ 1 Diplegia
☐ 2 Hemiplegia
☐ 3 Monoplegia
☐ 4 Paraplegia
☐ 5 Quadriplegia
☐ 6 Triplegia
☐ 7 Other

OBJECTIVES PLAN

(Write in coded values.)

	Long term*	Short term**	Needed—but unavailable
(27-74) Medical			
(27-74) Social development			
(27-74) Habilitative			

*Long term—one year or longer

**Short term—less than one year

SERVICES PLAN

(Write in coded values.)

	Long term*	Short term**	Needed—but unavailable
Evaluation			
Diagnosis			
Treatment			
Day Care			
Training			
Education			
Sheltered Employment			
Recreation			
Personal Care			
Domiciliary Care			
Special Living			
Counseling			
Information & Referral			
Follow Along			
Protective			
Transportation			

OBJECTIVES CODES

CODE	*OBJECTIVES*
1000	Medical Needs
1100	Health
1110	Disease
1120	Chronic Conditions
1200	Physical Development
1210	Motor Development
1211	Hand
1212	Arms
1213	Trunk
1214	Crawl
1215	Stand
1216	Walk
1220	Sensory Development
1221	Physical
1222	Perceptual

- 2000 Social Development
  - 2100 Self-help Skills
    - 2110 Toilet Training
    - 2120 Feeding and Drinking
    - 2130 Grooming and Dressing
  - 2200 Communication
    - 2210 Non-verbal
    - 2220 Verbal-comprehension
    - 2230 Verbal-development
  - 2300 Inappropriate Behavior
- 3000 Habilitation
  - 3100 Educational
  - 3200 Vocational
  - 3300 Independent Living
  - 3400 Job Placement

SERVICES CODES

CODE *SERVICES*

- 0100 Evaluation Services
  - 110 Physical
  - 120 Psychological
  - 130 Vocational
  - 140 Educational
  - 150 Social
  - 160 Economic
  - 170 Legal
  - 180 Environmental/Cultural
  - 190 Other
- 0200 Diagnostic Services
  - 210 Psychological Services
  - 220 Social Services
  - 230 Medical Services
  - 290 Other Services
- 0300 Treatment Services
  - 310 Surgical
  - 320 Psychiatry
  - 330 Dietary Control
  - 340 Chemotherapy
  - 350 Physical therapy
  - 360 Occupational Therapy
  - 370 Behavioral Modification
  - 380 Speech Therapy
  - 390 Counseling or Other Services
- 0400 Day Care Services
  - 410 Pre-School
    - 411 Creative Activities
    - 412 Social Activities
    - 413 Physical Activities
    - 414 Learning Activities

415 Personal Care
416 Training
417 Counseling
418 Recreational
420 School Age
421 Creative Activities
422 Social Activities
423 Physical Activities
424 Learning Activities
425 Personal Care
426 Training
427 Counseling
428 Recreational
430 Adult
431 Creative Activities
432 Social Activities
433 Physical Activities
434 Learning Activities
435 Personal Care
436 Training
437 Counseling
438 Recreational
0500 Training Services
510 Pre-School
520 School Age
530 Adult
0600 Education Services
610 Pre-School Special Ed
620 Pre-School Regular Ed
630 School Age Special Ed
640 School Age Regular Ed
650 Adult Special Ed
660 Adult Regular Ed
0700 Sheltered Employment Services
710 Evaluation
711 Part Time Not Paid
712 Part Time Paid
713 Full Time Not Paid
714 Full Time Paid
720 Work Adjustment
721 Part Time Not Paid
722 Part Time Paid
723 Full Time Not Paid
724 Full Time Paid
730 Occupational Skill Therapy
731 Part Time Not Paid
732 Part Time Paid
733 Full Time Not Paid
734 Full Time Paid

0800	Recreation Services	
	810	Self Expression
	820	Social Interaction
	830	Entertainment
0900	Personal Care Services	
	910	Provision of Food
	920	Provision of Shelter
	930	Provision of Clothing
1000	Domiciliary Care Services	
1100	Special Living Arrangements Services	
1200	Counseling Services	
	1210	Family
	1220	Vocational
1300	Informational and Referral Services	
1400	Follow-Along Services	
1500	Protective & Other Social and Socio-Legal Services	
	1510	Legal
	1520	Social
	1530	Other
1600	Transportation Services	

NOTIFICATION OF CHANGES IN LIVING PLAN/SERVICES

State ____________________________ __ __

DATE OF ACTION
__/__/__
Mo. Day Yr.

Agency ____________________________ __ __ __

Client's Case Number __ __ __ __ __ __ __ __ __ __

Social Security Number __ __ __ __ __ __ __ __ __ __

Sex ☐ 1 Male ☐ 2 Female

Name Code __ __ __ __ __ __ __ __

Birthdate __/__/__
Mo Day Yr.

CHANGES IN LIVING PLAN

FROM

☐ 00 New Client
☐ 01 State Institution
☐ 02 Private Institution
☐ 03 Independent Home
☐ 04 Parental/Relative Home
☐ 05 Sanitarium Care
☐ 06 Family/Foster Care
☐ 07 Nursery
☐ 08 Multiservice Facility
☐ 09 Prvt. Residential Fac.
☐ 10 Long Term Care
☐ 11 Training Hostel
☐ 12 Sheltered Workshop
☐ 13 Minimal Supervision Hostel
☐ 14 AWOL
☐ 15 Other Hospital
☐ 16 Day/Night Care
☐ 17 Other Plans

TO

☐ 00
☐ 01
☐ 02
☐ 03
☐ 04
☐ 05
☐ 06
☐ 07
☐ 08
☐ 09
☐ 10
☐ 11
☐ 12
☐ 13
☐ 14
☐ 15
☐ 16
☐ 17
☐ 99 Out of System

REASONS FOR CHANGE

☐ 01 Initiation
☐ 02 Alternate Plan
☐ 03 Inappropriate Plan
☐ 04 Unavailable
☐ 05 Imposed Plan
☐ 06 Reached Goals
☐ 07 Regression
☐ 08 Crisis
☐ 09 Withdrawn
☐ 10 Died

CHANGES IN SERVICES
(Write in appropriate service code—see code book.)

REASONS FOR CHANGES

Evaluation ____________
Diagnosis ____________
Treatment ____________
Day Care ____________
Training ____________
Education ____________
Sheltered EMP ____________
Recreation ____________
Personal Services ____________
Domiciliary Care ____________

Spec. Living Plan ______
Counseling ____________
Information and Referral _
Follow Along __________
Protective ____________
Transportation __________

REASONS FOR CHANGE

☐ 01 Initiation
☐ 02 Alternate Plan
☐ 03 Inappropriate Plan
☐ 04 Unavailable
☐ 05 Imposed Change
☐ 06 Reached Goals
☐ 07 Regression
☐ 08 Crisis
☐ 09 Withdrawn
☐ 10 Died

DATA COLLECTION SYSTEM

The preceding forms were designed to assess only the most basic characteristics of the client and are therefore more limited in scope than alternatives such as the AAMD Adaptive Behavior Scale, Vineland Social Maturity Scale, Cain-Levine Social Competency Scale, etc. Assuming sufficient manpower is available to administer this type of scale, the use of one of the more extensive scales is to be encouraged as they represent a better alternative for measuring adaptive behavior.

III. DATA COLLECTION SCHEDULE

A. *Initiation of Data File*

1. Establish Target Date

The target date is the time by which information described in 2a and 2b below has been gathered on all of the clients currently in the agency. At this point in time, the data file will be initialized and implemented on the computer system.

2. Present Caseload
    a. Complete the following on all clients currently in the caseload before the target date:
        (1) ***Intake Form*** (Form A)
        (2) ***Diagnosis and Evaluation Form*** (includes objectives and services plans–Form B)
        (3) ***Behavior Development Survey or Adaptive Behavior Test*** (Form C)
    b. Complete a ***Notification of Changes in Living Plan/Services Form*** (Form D) for all clients currently in the caseload as of the target date. This information will establish the client's living plan and the services being received by him at the time the data file is initialized.
    c. Initiate a ***Caseload Control Totals Form*** (see Example 1). The form should include totals for the current caseload broken down by living plans and sex or some other variable of your choice.

B. ***Updating of Data file***
1. New Clients
    a. Complete the following on all new clients entering the agency following the initialization of the data file:
        (1) ***Intake Form***
        (2) ***Diagnosis and Evaluation Form*** (includes objectives and services plans)
        (3) ***Behavior Development Survey or Adaptive Behavior Test***
        (4) ***Notification of Changes in Living Plan/Services Form***
2. Continuing Caseload
    a. When a client's type of service or living plan changes (i.e., termination of old plan and/or initiation of new one), complete a Notification of Changes in Living Plan/Services form.
    b. At yearly re-evaluation, complete a Behavior Development Survey form or its equivalent (i.e., Adaptive Behavior or other census form) as well as a new Diagnosis and Evaluation form for all clients. If re-evaluations are given for all clients in the caseload on an annual date, include a *Caseload Control Totals* form in the package of data, and send to headquarters. For re-evaluations given on an anniversary (birth, admission) date, send the re-evaluation data to headquarters as described below.

(EXAMPLE 1)

Caseload Control Totals

Agency Name ______________________________

Date: from ____/____/____ to ____/____/____
Mo. Day Yr. Mo. Day Yr.

Living Plans	Sex		Totals
	Males	Females	
1			
2			
3			
4			
5			
6			
7			
8			
9			
10			
11			
12			
13			
14			
15			
16			
17			
99			
Totals			

REFERENCE MANUAL

A. Name Code Description

To insure confidentiality of the clients in the data file and in order to create a unique tracking number by which an individual can be identified, an eight character code has been developed.

Name codes are requested on all forms and particular attention should be paid to their accuracy. The following table of the characters and their sources explains the coding system:

Character	*Source of Character*
1	The first letter of the client's last name
2	The third letter of the client's last name
3	The fourth letter of the client's last name
4-5	The total number of *letters* in the last name (Disregarding any spaces within the name, see example)
6	The first letter of the client's first name
7	The first letter of the client's second name (usually middle)
8	UNIQUE CODE: the characters 1-7 will uniquely identify most clients. In these cases, the eith character will be a 9. However, to differentiate multiple births (i.e., twins, triplets, etc.) or other clients with matched name codes (1-7), this eighth character should be assigned as follows: first matched client = 9, second matched client = 8, third matched client = 7, etc. (see examples following).

Examples

Name	*Name Code* (8 characters)	
1. Barrymore, John Drew	BRR09JD9	
2. Doe, William	DE OOW 9	Twins
Doe, Wendy	DE OOW 8	
3. MacDonald, Robert E.	MCDO9RE9	Surname with a space,
McDonald, John A.	MD008JA9	disregard space
4. McGunigle, Joyce Ann	MGUO9JA9	

NOTE: In coding last names with less than four characters, leave the 3rd position blank (as in example 2). Also for person's with only one given name, leave position 7 blank. DO NOT fill in blanks with zeros. There must be 8 positions for each name code.

B. Discussion of Diagnosis Coding

The mentally retarded clients are to be diagnosed according to the AAMD (American Association on Mental Deficiency) classifications. We would like to suggest adapting those codes to the proposed data collection by using a 15-digit code when assigning a diagnosis. The code would be broken down as follows:

Digits	
1-3	ICD codes (310-315)
4-6	AAMD codes (000-990) for primary diagnosis
7-15	AAMD codes for the expanded diagnosis

The position of the codes in the last nine digits would determine the category it represents, i.e., the 7th digit would be the code for genetic component, the 8th digit would represent secondary cranial anomaly, the 9th digit is for impairment of special senses, etc.

Epileptic and cerebral palsied diagnoses vary and are less standardized. In an attempt to use a common system, the ICD (international Classification of Diseases) is suggested. For disabilities diagnosed as other than mental retardation, epilepsy or cerebral palsied, the ICD manual should also suffice.

Adapted *ICD CODES*[1]

(INTERNATIONAL CLASSIFICATION OF DISEASES)

343.0000	Cerebral spastic infantile paralysis
343.1000	Cerebral
343.1100	infantile palsy
343.1200	spastic infantile paraplegia
343.2000	Little's disease
343.3000	Paralysis due to birth injury
343.3100	intracranial
343.3200	spinal

- 343.4000 Spastic
  - 343.4100 diplegia NOS
  - 343.4200 Paralysis NOS
- 343.5000 Diplegia
  - 343.5100 infantile
    - 343.5110 spastic
    - 343.5120 cerebral
    - 343.5130 spinal
- 343.5200 congenital
  - 343.5210 spastic
  - 343.5220 cerebral
  - 343.5230 spinal
- 343.6000 Hemiplegia
  - 343.6100 infantile
    - 343.6110 spastic
    - 343.6120 cerebral
    - 343.6130 spinal
  - 343.6200 congenital
    - 343.6210 spastic
    - 343.6220 cerebral
    - 343.6230 spinal
- 343.7000 Monoplegia
  - 343.7100 infantile
    - 343.7110 spastic
    - 343.7120 cerebral
    - 343.7130 spinal
  - 343.7200 congenital
    - 343.7210 spastic
    - 343.7220 cerebral
    - 343.7230 spinal
- 343.8000 Paraplegia
  - 343.8100 infantile
    - 343.8110 spastic
    - 343.8120 cerebral
    - 343.8130 spinal
  - 343.8200 congenital
    - 343.8210 spastic
    - 343.8220 cerebral
    - 343.8230 spinal
- 343.9000 Tetraplegia
  - 343.9100 infantile
    - 343.9110 spastic
    - 343.9120 cerebral
    - 343.9130 spinal
  - 343.9200 congenital
    - 343.9210 spastic
    - 343.9220 cerebral
    - 343.9230 spinal
- 344.000 Other cerebral paralysis
  - 344.1000 Diplegia NOS–long standing–unspecified cause
  - 344.2000 Hemiplegia NOS–long standing–unspecified cause

344.3000	Paralysis NOS–long standing–unspecified cause
344.4000	Paraplegia NOS–long standing–unspecified cause
344.5000	Paresis NOS–long standing–unspecified cause
344.6000	Posthemiplegic chorea NOS–long standing–unspecified cause
345.0000	Epilepsy
345.1000	General non-convulsive
345.1100	epileptic absence
345.1200	minor epilepsy
345.1300	petit mal (ideopathic)
345.1400	pykno-epilepsy
345.2000	General convulsive
345.2100	epileptic seizures
345.2110	clonic
345.2120	myoclonic
345.2130	tonic
345.2140	tonic-clonic
345.2200	grand mal (idiopathic)
345.2300	major epilepsy
345.3000	Status epilepticus
345.3100	epileptic absence status
345.3200	grand mal status
345.3300	petit mal status
345.3400	epilepsia partialis continua (Kojevnikov)
345.3500	status epilepticus
345.3510	generalized (convulsive)
345.3520	generalized (non-convulsive)
345.3530	partial
345.3540	any type seizures
345.4000	Partial
345.4100	epilepsy
345.4110	Bravais-Jacksonian
345.4120	focal
345.4130	Jacksonian
345.4140	motor partial
345.4150	partial-secondary generalized
345.4161	psycho-motor
345.4162	psycho-sensory
345.4171	somato-motor
345.4172	somato-sensory
345.4180	visceral
345.4190	visual
345.4200	epileptic automatism
345.9000	Other and Unspecified
345.9100	epilepsy NOS
345.9200	epileptic convulsions
345.9300	epileptic
345.9310	fits NOS
345.9320	seizures NOS

DEFINITIONS OF OBJECTIVES

1000 ***Medical Needs***

Care of a medical or therapy nature which is needed by the client. It usually refers to a long term or chronic condition which must be attended to before other needs of the client can be met.

1100 ***Health***

The relief of poor health conditions which prevent the client from obtaining service for other needs.

1200 ***Physical Development***

Development of motor and sensory abilities to the extent that they will enable the client to perceive and respond to his surrounding environment.

2000 ***Social Development***

Development of skills, communication, and improvement of behavior to the extent that the client can appropriately interact with others in the milieu.

2100 ***Self-Help Skills***

Development of skills such as toilet-training, feeding, and dressing which normally are carried out independently.

2200 ***Communication***

Development of non-verbal and verbal language skills, permitting both comprehension and communication of information.

2300 ***Appropriate Behavior***

Elimination of inappropriate behaviors which interfere with the development of other skills and which cause social friction.

3000 ***Habilitative***

Development of more formalized skills which approach those of the normal society.

3100 ***Education***

Learning reading, writing, and related skills.

3200 ***Vocational***

Training for skills necessary to fulfill job requirements.

3300 ***Independent Living***

Development of skills necessary for enabling the client to care for himself in the community.

3400 ***Job Placement***

Acquisition and maintenance of a paying job in the community.

DEFINITIONS OF SERVICES

0100 ***Evaluation Services*** – The application of techniques for the systematic appraisal of pertinent physical psychological, vocational, educational, cultural, social, economic, legal, environmental and other factors of the developmentally disabled individual and his family, (1) to determine how and to what extent the disabling conditions may be expected to be removed, corrected or minimized by services; (2) to determine the nature and scope of services to be provided; (3) to select the service objectives which are commensurate with the developmentally disabled individual's interests, capacities and limitations; and (4) to devise an individualized program of action; to be followed, at the intervals needed, by periodic reappraisals.

The particular techniques to be used will depend on the particular service to be provided and on personal factors such as the developmentally disabled individual's age and functional level, primary and other disabilities, among others.

0200 ***Diagnostic Services*** – The provision of coordinated services, including, but not limited to, psychological services, social services, medical and other services necessary to identify the presence of a developmental disability, its cause and complications, and to determine the extent to which the disability limits (or is likely to limit) the individual's daily living and work activities.

0300 ***Treatment Services*** – Provision of coordinated interventions which halt, control or reverse processes which cause, aggravate or complicate developmental disabilities. The interventions may include dental and medical treatments, such as surgical procedures, psychiatry, dietary controls, or chemotherapy; physical therapy; behavioral modification (as defined by the American Psychological Association); speech therapy; counseling and others as indicated by the needs of the developmentally disabled individuals being served.

0400 ***Day Care Services*** – Comprehensive and coordinated sets of activities providing personal care and other services to preschool, school-age and adult developmentally disabled individuals outside of their own homes during a portion of a 24-hour day. Services include a variety of creative, social, physical and learning activities based on an appropriate evaluation and designed to provide at least personal care, training, counseling and recreation services carried out under careful supervision. They may be organized as either:

410-420 Developmental Services for Children

Activities emphasizing maturation of children and supplementing the services being provided by their parents or parent surrogates; or

430 Activity Programs for Adults

Activities which emphasize occupational and social goals which assist adults to become as self-dependent as possible and to make constructive use of leisure time.

Day Care services may be appropriate for developmentally disabled children not yet ready for formal training programs, for children who need supervision after school hours (including weekends and vacation periods) and for developmentally disabled adults too severely handicapped to participate in education, training or sheltered employment services. Day Care services must provide more than supervision. The program must provide activities which will minimize handicaps and encourage functional development. Day Care differs from Training in the purpose, focus and intensity of its programming. It is intended to approximate the stimulation and training which can be provided by knowledgeable, concerned parents. For adults, Day Care should provide pleasant and constructive occupations which have meaning to the adults involved and encourage continuing development.

0500 *Training Services* – Provisions of a planned and systematic sequence of instruction in formal and informal activities based on appropriate evaluation and objectives, designed to (1) develop skills in performing activities of daily living including self-help, motor and communication skills; (2) enhance emotional, personal and social development, or (3) provide experiences for gaining useful occupational and pre-vocational skills.

Training Services may be provided to pre-school children to accelerate development and to compensate for deficiencies related to their disabilities; to school-age children not yet ready for or excluded from formal education services; and for adults who need occupational skills but whose abilities severely limit their work output.

0600 *Education Services* – Provision to developmentally disabled children and adults not eligible for public school classes (regular or special) or structured learning experiences, based upon appropriate evaluations, through the use of a broad and varied curriculum of practical academic subjects primarily designed to develop ability to learn and acquire useful knowledge and basic skills, and to improve the ability to apply them to everyday living.

0700 *Sheltered Employment Services* – Provision of a structured program of activities involving work evaluation, work adjustment, occupational skill training and paid, part-time or full-time employment for those who cannot be readily absorbed into the labor market because of severe disability(ies). Such services may be provided in a center or in the developmentally disabled individual's place of residence.

0800 *Recreation Services* – Provision of planned and supervised activities designed to (1) help meet specific individual therapeutic needs in individual self-expression, social interaction and entertainment; (2) develop skills and interests leading to enjoyable and constructive use of leisure time; and (3) improve well-being.

0900 *Personal Care Services* – Services designed to maintain health and well-being, including the provision of food, shelter and clothing as required, to prevent regression and other complications. Personal Care services must be provided in conjunction with one or more other appropriate services.

1000 *Domiciliary Care Services* – Provision of living quarters, personal care, and supervision for persons needing care on a 24-hour-a-day basis.

Domiciliary Care Services differ from Special Living Arrangements by the degree of supervision and the amount of Personal Care provided. It may be provided in such quarters as nursing homes, foster homes, or other residential facilities.

1100 *Special Living Arrangements Services* – Provision of living quarters for persons who need some degree of supervision. Special Living Arrangements services must include at least Counseling and leisure-time activities.

Special Living Arrangements services are for developmentally disabled persons who can leave the place of residence, for work, recreation or other reasons. Such persons will probably not be heavily dependent on Personal Care services, which may be less intense than in Domiciliary Care, or may be omitted, depending on the needs of the persons served.

1200 *Counseling Services* – Giving of professional guidance on the basis of knowledge of human behavior and the use of special inter-personal skills to achieve specified goals, such as making a determination of appropriate resources; assisting the developmentally disabled individual and his family to understand his capacities and limitations; setting of short and long range goals, including vocational; and providing solutions to problems that interfere with the developmentally disabled individual's participation in needed services. The professional discipline of the counselor will depend on the goals and nature of the counseling service.

1300 ***Information and Referral Services*** – The basic service is the provision of an up-to-date, complete listing of all appropriate resources from which appropriate selections can be made available and quickly accessible to professional persons serving the developmentally disabled individual and his family. It is important that a professionally responsible person be the point of contact between the individual or family and the Information and Referral Services, so that it may be advisable to provide a counseling service in connection with the I & R Service. It is also highly advisable for a skilled, professional person to develop the listing of services in order to provide proper linkages with the other agencies; but it is not necessary for the staff who searches the listings for particular resources to be professional.

The I & R Service can also develop Public Information activities with regard to the problems of Developmental Disability.

1400 ***Follow-Along Services*** – Establishment and maintenance of a counseling relationship on a lifelong basis with developmentally disabled individuals and their families, as desired, for the purpose of assuring that anticipated changes in needs and/or needs arising from crisis are recognized and appropriately met.

1500 ***Protective and Other Social and Socio-legal Services*** – Provision of a system of continuing legal, social and other appropriate services designed to assist individuals who are unable to manage their own resources or to protect themselves from neglect, exploitation or hazardous situations without assistance from others and to help them exercise their rights as citizens.

1600 ***Transportation*** – Provision of necessary travel and related costs in connection with transporting developmentally disabled individuals and where necessary members of their families, to and from places in which they are receiving other services. Transportation may also include taking services to the homebound as well as delivery of raw materials and pickup of the finished product from homebound industries, where indicated.

LIVING PLAN CODES

CODE	*LIVING PLANS*
01	State institution/State Training School for M/R
02	Private Institution for the Mentally Retarded
03	Independent Home
04	Parental Home/Relative Home/Legal Home
05	Sanitarium Care
06	Family/Foster Care
07	Nursery
08	Multiservice Facility

09 Private Residential Facility/Group Home/Board and Care
10 Long Term Care /Convalescent Home/Convalescent Hospital/Aged Home, etc.
11 Training Hostel/Halfway House
12 Sheltered Living Hostel/Sheltered Workshop
13 Minimal Supervision Hostel
14 Absent Without Leave (AWOL)
15 Other Hospitals
16 Day/Night Care
17 Other Plans
99 Out of System

DEFINITION OF LIVING PLANS

The categories below represent an attempt to define plans which are as mutually exclusive as possible. Living plans will still exist which may appear to be a combination of those below, i.e., facilities may exist that have elements of several plans. Living Plan, however, refers to the plan for the *client* and not, strictly speaking, a description of the facility. Use the "other" category only as a last resort for exceptionally unusual situations.

01 ***State Institution/State Training School for M/R***—Administered by State

02 ***Private Institutions for the Mentally Retarded***—Differentiated from other plans by non-reliance on community for any services; a full service facility.

03 ***Independent Home*** – Client or spouse head of household.

04 ***Parental Home/Relative Home/Legal Home***

05 ***Sanitarium Care*** – Patients under this type of plan should not need the daily attention of professional staff, but are crib bound. This means that they are under 40" in height and under 40 lbs. in weight. Typically, sanitarium care residents are reasonably healthy, small, infirm infants.

06 ***Family/Foster Care*** – Unspecialized home for ambulatory children and adults which offer a family setting for optimal normal life. Dependent upon community services for education, recreation, vocational training and medical services. Usually no more than 4-6 persons at each facility.

07 ***Nursery*** – Specialized for non-ambulatory children between 0-5 (or older who will *fit into cribs*) who are multihandicapped, severely and profoundly retarded. Operators are not professionally trained. Dependent on community services for acute medical care and training or therapy provided. Differs from Sanitarium Care in that reliance upon community services for medical treatment is more acute because children are in poorer health.

08 ***Multiservice Facility*** – Specialized for non-ambulatory, multihandicapped children and adults who do require 24-hour nursing services by professional nurses. Dependent upon community services for acute medical care, but may provide therapy on premises. No size or weight restriction.

09 ***Private Residential Facility/Group Home/Board and Care***—Group living, non-specialized service for ambulatory children, or for ambulatory adults. Dependent upon community services for education, recreation, vocational training, and medical care. Patients typically need minimal supervision and would not benefit from family setting.

10 ***Long Term Care/Convalescent Home/Convalescent Hospital/Aged Home etc.***—Residential setting staffed by medical and nursing personnel to meet

needs of medically impaired multihandicapped adults and children, but largely adults. recreation and rehabilitation services may be offered on premises. Differs from multiservice facility and nursery by not being dependent on community for medical care. Differs from hospitals for the mentally retarded in that not all services are offered.

11 ***Training Hostel/Halfway Houses***–For those 16 years of age and older. Active involvement in vocational training. Placements are short term in preparation for adult living.

12 ***Sheltered Living Hostel/Sheltered Workshop***–Sixteen years old and up. Long term sheltered work or day activity with supervised daily living accommodations.

13 ***Minimal Supervision Hostel***–Eighteen years old and up. For socially adequate young adults who are semi-independent, but require supervision and consultation in crisis situations.

14 ***Absent Without Leave (AWOL)*** – At least overnight absence. Applies only to institutions.

15 ***Other Hospitals***–General hospitals, county hospitals, V.A. hospitals, clinics, medical schools, etc. Placement in this facility is expected to be temporary, and is in response to a special situation, which when resolved will result in replacement.

16 ***Day Care or Night Care***–This category includes placements which are as much for the convenience of the parents as for the patients. When not on day or night care, the patient lives at home.

17 ***Other Plans***–This category includes placements which do not fit into any of the categories outlined above.

99 ***Out of System***–Client is no longer a part of the caseload either through discharge or death.

REASONS FOR CHANGE CODES

CODE	*REASONS FOR CHANGE*
01	Initiation
02	Alternate plan
03	Inappropriate plan
04	Unavailable
05	Imposed plan
06	Reached goals
07	Regression
08	Crises
09	Withdrawn
10	Died

DEFINITION OF REASONS FOR CHANGE IN SERVICE AND LIVING PLAN

01 ***Initiation***–Client is started on a new service/living plan, one which is best suited to meet his needs.

02 ***Alternate Plan***–Termination of service/living plan because an alternate service/living plan, one which is more suited to his needs, has become available.

03 ***Inappropriate Plan***–Termination of service/living plan because it does not meet the needs of the client or is not producing the desired benefits.

04 ***Unavailable***–Termination of service/living plan because it is no longer available.

05 ***Imposed Change***–Termination of service/living plan for a reason unrelated to client's progress (administrative, incarceration, draft, etc.)

06 ***Reached Goals***–Termination of service/living plan because the client has progressed as far as he can under the present arrangement.

07 ***Regression***–Termination of service/living plan because the client has regressed to a point where the service being offered is no longer appropriate to his needs.

08 ***Crisis***–Termination of service/living plan due to an emergency situation involving the client.

09 ***Withdrawn***–Termination of service/living plan because the client has been removed from the system.

10 ***Died***–Termination of service/living plan because the client has died.

Part III
Reaching Special Populations Among the Developmentally Disabled

Editor's Notes

When Senate hearings were held on the initial Developmental Disabilities legislation in 1969, then Assistant HEW Secretary for Legislation, Creed C. Black, testified that a study of the 166 projects funded under the Mental Retardation Facilities Construction Act (P.L. 88-164) showed that only 12 facilities were located in poverty areas. He added that this fact could "hardly be called reassuring in light of the knowledge that 75 percent of all retarded persons are located in such areas."*

The linkage between poverty and the incidence of mental retardation and other developmental disabilities has received wide attention in professional circles over at least the decade. Yet, as the President's Committee on Mental Retardation has pointed out, there continues to be a dirth of available services in low income neighborhoods.

The papers prepared by Kelly E. Miller and Armando Sanchez both explore the special problems developmentally disabled individuals living in disadvantaged communities face in obtaining adequate services. Both authors stress the close relationship between the lack of services for the developmentally disabled in deprived neighborhoods and the general shortage of humane health, education, welfare and social services available to the poor.

Miller describes the general difficulties faced by the urban poor in receiving human services as well as the special problems encountered by inner city representatives in Philadelphia in learning about the Pennsylvania Developmental Disabilities program. He also outlines several proposals for aiding inner city residents of Philadelphia provided adequate funding can be obtained.

Sanchez suggests that Chicanos and other minority groups are denied a "healthy living environment by social class circumstances and professional prejudice in health care." He condemns what he calls "an Anglo middle class syn-

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**Mental Retardation and Other Developmental Disabilities, 1969*: Hearings before the Subcommittee on Health of the Senate Committee on Labor and Public Welfare, November 10 and 11, 1969, page 113.

drome" in health services and the tendency of most health systems to develop programs which work at cross purposes with the social, cultural and organizational structures of minority communities. A specific example is cited by the author to indicate how such discrimination operates—often in subtle, subliminal forms—in the case of an HEW study of minority group needs for rehabilitation and developmental disabilities services.

Sanchez notes that health professionals frequently overlook the fact that there is not one but several Chicano "communities" within any given neighborhood. To overlook this fact, he suggests, is to predestine many well intended human service programs to failure. He concludes with a series of six recommendations for social planners who are seriously interested in mounting successful programs in Mexican-American communities.

James MacDonald Watson deals with a somewhat different yet related problem of accessing services for the developmentally disabled: how do we reach the DD population in rural areas? According to the U.S. Census Bureau, despite the continuing trend toward urbanization, in 1970 some 54 million persons lived in rural America. Watson points out the general problems faced in mounting effective programs for persons afflicted with conditions such as developmental disabilities. Not only does the low incidence of the disorder make it hard to establish an adequate service base within reasonable commuting distance but the generally low per capita income in rural areas and the built in discrimination of most population-based public funding formulae further exaggerate the problems involved.

Watson describes several unique uses of DDSA funds in Oregon to stimulate service outreach to developmentally disabled persons in rural sections of the state. He also suggests the broader use of paraprofessionals and electronic technology (television and telephone circuits) as ways of reaching and servicing isolated segments of the DD population. Another exciting new approach proposed by the author is the use of television cassettes as a home training device for the developmentally disabled and their families. Watson closes with a few comments on the need for "togetherness" among the special interest groups represented on state DDSA councils.

Services for the Developmentally Disabled Within the Inner City

Kelly E. Miller

INTRODUCTION

A Statement of the Problem

Senator Edward M. Kennedy stated in the foreword of a book written by Rodger Hurley entitled *Poverty and Mental Retardation: A Causal Relationship,*

> There is a lot to be done in America if we are to reach a goal set for us almost two centuries ago—and a truly revolutionary goal it was, to dare insist upon "Life, liberty, and the pursuit of happiness" for each and every one of our citizens. Clearly, not all of us even today, however rich and mighty our nation is, have the kind of freedom, the kind of opportunities, to let a person fulfill the dreams a man like Thomas Jefferson had for all his countrymen.

Rodger Hurley states,

> among the conditions which have blighted American life, two of the most perplexing have been poverty and mental retardation. The harshness of each has been aided by a good deal of public ignorance and, until recently, each has been treated with a large degree of public apathy. A relationship between the two has rarely been made apparent, each has in fact, been similarly relegated to regions beyond the American conscience.

The thinking of "experts" concerning poverty and mental retardation is even more tragic than the ignorance of the general public. Unfortunately, many such experts harbor prejudiced opinions as to the importance of heredity in causing mental retardation, and in turn they equate poverty with genetic inferiority. Although one can understand the difficulty of the professional in bridging the gulf between his middle class orientation and that of the poor, it might be expected that professional training would enable him to overcome his ignorance and prejudice. Kennedy further states,

> There is indeed something self-serving about the way we often tend to think of the poor, and in particular those among us we all too conveniently choose to call "mentally retarded." The term has about it, for many of us, a final unyielding quality; it is as if an irreversible hand of fate has been at work, and now the deed is done, the judgment pronounced, the person's mind declared "retarded"—and that is that.
>
> The rest, we say, is a custodial matter, or the rest is up to the particular families of the retarded, who will surely do the little that can be done, will surely help the retarded in the small and undramatic ways they can be helped. Such an attitude will not do, not if we take a careful look at the facts.
>
> There are millions and millions of people who, to a very significant extent, are waiting. They are waiting for the rest of us to know what is already known, but more important, to do what can and ought to be done. For the fact is that only a small number of children called "retarded" cannot profit substantially from various kinds of special attention.
>
> What is more, most children called "retarded" are not suffering from an injury or an inherited deficit but from what might be properly called a kind of political, social and moral retardation affecting the rest of us. The supposed mental retardation in many of the poor is not mental retardation at all but environmental deprivation, which includes being served by institutions that do not perform in the way the public believes they do. It appears that on many occasions we are not measuring mental retardation but our society's callousness towards the poor.
>
> Mr. Hurley indicates that, "There is no known or irreversible cause for over 90% of the mental retardation in America—unless the cause be in fact a number of all too remediable social and economic forces that become translated, ultimately, into personal tragedies. Abstractions like "Poverty" and "Prejudice" eventually get translated into the terribly sad psychological experiences of children who are called "backward" or "slow" or "dumb" or (by more sophisticated people) "retarded," when in fact they have gone hungry and become malnourished, and have been neglected and rebuffed and scorned and humiliated and made to feel unwanted and virtually subhuman.

No wonder, then, that hundreds of thousands of American children come to school and appear all too quiet, even dazed, or demonstrate confused and erratic behavior. Often they have from the very start lacked things—adequate medical care, the right food, a house that protects its inhabitants from the cold weather and from mosquitoes and flies and rats, and in general, a neighborhood where children are safe, where their lives are held important, where their needs are met as a matter of course, and certainly as a matter of conscience. Of course, such children become hurt and sad. Of course such children feel deep down inside a general doubt about the world, a mistrust of schools, of lessons that are assigned and explained, and of teachers who then test and grade them. It is natural that such children are labeled "retarded" and sent off here, there, anywhere—so long as they will be out of sight, out of our minds. Then we can always content ourselves with the knowledge that we have done the best we can, taking pains to look at them and test them and send them to those special classes which all to often treat symptoms (and even these in a superficial way) rather than true causes.

Perhaps the deliberations of this conference will help those children—one can only hope and pray so. It is hoped that the indignation that many of us find growing within ourselves, particularly those of us who are considered "experts" will turn into something else. A whole new climate of opinion is needed in this nation that will enable the Congress to act, to pass the laws needed if American children of all races and creeds are no longer to be labeled and in essence ignored. Instead we want children who are challenged finally to display their long hidden and neglected and overlooked possibilities, their humanity, really, which has been tragically squandered, to their loss and to our shame.

Definition of Developmental Disability

What is a developmental disability? Is it a mental, physical, emotional or spiritual state of being or is it a combination of all these inputs? On October 30, 1970, President Nixon signed into law the Developmental Disabilities Services and Facilities Construction Amendments of 1970. This new legislation significantly expanded the scope and purposes of the Mental Retardation Facilities Construction Act of 1963, as amended, and marked a new phase in the Federal Government's efforts to provide a better life for all mentally retarded and other developmentally disabled citizens. It was designed to provide the states with broad responsibility for planning and implementing a comprehensive program of services and to offer local communities a strong voice in determining needs, establishing priorities and developing a system for delivering services.

The Developmental Disabilities Act of 1970 defines developmental disability to mean "a disability attributable to mental retardation, cerebral palsy, epilepsy, or other neurological handicapping conditions of an individual found to be closely related to mental retardation or to require treatment similar to that required by mentally retarded individuals. In addition:

- the disability must have originated before such individual attains age 18.
- must have continued, or be expected to continue indefinitely.
- and must constitute a substantial handicap to such individuals.

As Child Advocates we should be concerned and interested in all services that provide for the health and welfare of all children, but particularly those who are handicapped and mentally retarded. It is hoped that the Developmental Disabilities Act will be utilized by those individuals and organizations sensitive to the needs of this special class of children.

As Child Advocates we must be concerned about the total environmental conditions which affect these children in all phases of their childhood as we attempt to improve their sense of well being and concept of self worth. Federal support for a wide range of diversified services in terms of lifetime human needs of the developmentally disabled is a prime concept of the Act. It provides for the comingling of funds under this program with those of State programs.

This facilitates the development of comprehensive services for the developmentally disabled through the combination and integration of the efforts in both specialized and generic services of several State agencies representing diverse areas such as health, welfare, education and rehabilitation, without imposing a set pattern of services on any one state.

Services for persons with developmental disabilities means specialized services directed towards the alleviation of a developmental disability or towards the social, personal, physical, or economic habilitation or rehabilitation of an individual affected by such a disability.

The term services includes: diagnosis, evaluation, treatment, personal care, day care, domiciliary care, special living arrangements, training, education, sheltered employment, recreation, counseling, protective and other social and socio-legal services, information and referral, follow along and transportation.

"Historically," according to Dr. Ruttenberg, Director of the Developmental Center For Autistic Children, "the Developmental Disabilities Act is an expansion from mental retardation legislation, an expansion which embraces a much wider range of developmental disabilities."

The trend around the country and even at the Attorney General's level in Pennsylvania is to place a broader, rather than narrower, interpretation to the scope. The general impression, although it cannot be documented, is that recent interpretations of developmental disabilities–for instance the "mandate" that evolved from the suit initiated by the Pennsylvania Association for Retarded Children (By September, 1972 *every* mentally retarded child, below 21 years of age must be provided with a free public program of training and education suitable for his learning capacities–include autistic children inasmuch as there is evidence that developmental predispositions, some on a congenital or perinatal basis, exist in the majority of cases.

The Developmental Disabilities Act authorizes grants for:

- developing and implementing a comprehensive and continuing plan.
- providing services to the developmentally disabled.
- constructing facilities for the housing of services.
- training of specialized personnel for services and research.
- developing or demonstrating new or improved techniques of service.
- constructing "university-affiliated facilities" for the interdisciplinary training of professional personnel.
- providing demonstration and training grants.

Legislative History of P.L. 91-517

Title I of P.L. 91-517 replaces existing authority (Part C, Title I, P.L. 88-164) to aid in the construction of community facilities for the mentally retarded with a combined formula and project grant program covering both construction of facilities and the provision of services to persons with developmental disabilities. The scope of the present program is broadened to include not only the mentally retarded but also persons suffering from other serious developmental disabilities originating in childhood including cerebral palsy, epilepsy, and other neurological handicapping conditions. It is estimated that 8.7 million children and adults–or 1/24 of the nation's population–suffer from developmental disabilities. Of this number, approximately 6 million are mentally retarded, 1 million are epileptics, 700,000 suffer from cerebral palsy and 1 million from other neurological handicaps originating in childhood (other than blindness and deafness). In the case of serious developmental disabilities, it is quite common for an individual to be afflicted with two or more overlapping conditions. In general, the more serious the disability, the more likely that the individual will be multiply handicapped.

The new legislation also extends the present authority to construct university affiliated facilities for the mentally retarded (Part B, Title I, P.L. 88-164) through June 30, 1973, and authorizes a new project grant program to cover the costs of administering and operating demonstration facilities and interdisciplinary training programs in such facilities (Title II, P.L. 91-517).

Existing authority to construct community mental retardation facilities is replaced by a broad new federal-state grant-in-aid program to assist the states in developing and implementing a comprehensive plan for meeting the needs of persons with developmental disabilities. States may use these funds to construct facilities, provide services, support state and local planning, administration and technical assistance, train specialized personnel and develop and demonstrate new service techniques.

Sixty million dollars is authorized to be appropriated for this program in fiscal year 1971, $104 million in FY 1972, and $130 million in FY 1973.

Hahnemann Catchment Area Demonstration Program

An example of a demonstration program is provided within Hahnemann catchment area which is one of the most economically and socially deprived areas in the State of Pennsylvania. This area in the City of Philadelphia, has the highest percentage of conditions associated with mental retardation and neurological damage in young children: i.e., low rate of prenatal care, high incidence of pregnancies in young girls, poor physical health of mothers, high rate of malnutrition, low education, high rate of unmarried mothers, etc.

Based on previous studies it is estimated that of the 2,000 children born each year in the Hahnemann catchment area more than 7% are developmentally disabled. In addition to the medical conditions which predispose infants to being at high risk at birth, the social and family disorganization associated with poverty, crime, and high drug abuse markedly interferes with the supportive environment which the new born needs. The social circumstances of the Hahnemann catchman area tend to interfere with the development of a continuing and close relationship with one competent, loving person which every child needs but particularly the handicapped child.

As a result, special difficulties are apt to arise due to the lack of maternal sensitivity to the special needs of the child. If the mother is young and unsupportive, if she has undue medical problems, if she has anxieties as a consequence of social problems, she will have difficulty establishing the close maternal bond necessary for providing the child the understanding and positive handling which he needs. It will be difficult for her to seek out and/or utilize all the special services necessary to foster the growth and development of her child.

Because failure to thrive is related to poor maternal care, malnutrition, genetic characteristics, social and economic frustrations, and lack of a stimulating environment, Hahnemann Hospital is proposing a model of services to confront these conditions. A proposal has been submitted to the State DDSA Agency to meet the need for: (1) the coordination of services as they impinge upon mothers and infants at high risk, (2) the establishment of the necessary collaborative arrangements with other significant child care and socializing agencies in the community, and (3) the direct habilitation services to the mothers and children not presently being served.

PRE-CONFERENCE MEETING

Issues, Problems, Services

In preparation for the National Conference of State Planning Advisory Councils on Services and Facilities for the Developmental Disabled, a pre-conference meeting was convened by the Child Advocacy Project of the Philadelphia Urban League in an effort to provide an accurate description of the issues, problems, and services available to developmentally disabled children in Philadelphia.

The pre-conference meeting was held on Wednesday, October 18, 1972 in the office of the Philadelphia Urban League, conference room #320. Representatives of more than 50 agencies serving developmentally disabled children were invited to attend. This paper represents a synthesis of the thinking which came out of that meeting.

One of the initial points of discussion was that none of the representatives at the meeting had been invited to attend the National Conference in Washington. The consensus was that the conference should be open to any and all agencies who are directly involved in providing services to developmentally disabled children. Future conferences sponsored by the National Advisory Council should ensure that all agencies have an opportunity to participate.

Pennsylvania Developmental Disabilities Advisory Council

The participants at the pre-conference meeting clearly indicated that they were confused about the Pennsylvania State Plan. Many did not even know of the existence of such a plan.

The facts, according to Mr. Jack Boyle, Planning Director of the Pennsylvania Developmental Disabilities Council, are that two State Plans for Pennsylvania were developed and approved and the State Plan for the 72-73 fiscal year has been presented to Mr. Francis Warren, Regional Commissioner, Department of Health, Education and Welfare, Region III, Philadelphia, Pennsylvania.

The original plans were hastily developed to meet immediate contingencies which caused a communications gap and confusion at the local level about the contents and status of the State Plan. There was also great concern about the lack of adequate guidelines. Mr. Boyle emphasized, however, that guidelines are not provided until after a letter of intent has been submitted.

On July 14th agencies were notified that a letter of intent must be submitted by August 15th. By the time the letter got there, two or three weeks had passed. There was no response to a letter of intent or acknowledgment for the tremendous efforts that were utilized.

During the 1970-71 fiscal year $551,134 was available to Pennsylvania. $517,517 was allotted of which $200,000 in seed money went to Philadelphia for planning purposes. A total of $416,297 has been allocated in the 1971-72 fiscal year.

A number of proposals from Philadelphia were submitted for approval. Four of these proposals were approved for funding by the State Developmental Disabilities Council. United Cerebral Palsy of Philadelphia and St. Christopher's Hospital for Children were eventually funded. According to Mr. Boyle, funds for Haven House and Mercy-Douglas Hospital were not released at the county level because they did not have the required contract with the County Administrator, Mental Health and Mental Retardation. The money was recalled and held in escrow for all four projects until the problems were ironed out. One of the problems has been identified as political. The County Administrators are the mechanism for disbursing Developmental Disabilities funds at the local level and are accountable for these funds and it is their responsibility to review and comment on need and feasibility of application originating through non-profit facilities within their respective purviews.

The programs at St. Christopher's Hospital and United Cerebral Palsy are now operational. When it became apparent that Mercy-Douglas Hospital was in serious financial difficulty, hospital administrators rejected the proposal. Because of the dual nature of the proposal, the Haven House program was affected. The money has now been returned to the state level for these two programs.

A major problem in the implementation of the Pennsylvania State Plan was the apparent conflict which existed between the State Council and the Administrative Agency, the Department of Public Welfare. The primary concerns are the lack of visibility and viability of the Council. Many agencies within the Commonwealth do not even know of the existence of the Developmental Disabilities Advisory Council. To correct this problem the Pennsylvania Council voted to change the administrative agency authority to the Governor's Office for Human Resources. Clear cut interpretation of the roles and authorities between the Council and the Administrative Agency should be spelled out. Prompt and adequate staffing should be provided if the Council is to discharge its functions properly.

North Central Philadelphia Community Mental Health and Mental Retardation Center

According to Mrs. Catherine D. Weis, Director of Mental Retardation Services, Children and Family Unit of the North Central Philadelphia Community MH/MR Center,

> At one time staffing grant authority was available at the regional level through the Social and Rehabilitation Service. SRS funding was phased out with the intention that the

> expanded Developmental Disabilities Act would be phased in. The problem was that the timing of phasing out of one project and phasing in of the other did not mesh.
>
> There was a real delay in getting guidelines to the local community and agencies and a new routing for grant applications. In other words, previously grant applications were submitted via the Regional Office of HEW. Whereas, now grant applications are submitted via the County and State Regional Offices to Harrisburg. The real hooker has been the small amount of money that was made available in the State of Pennsylvania which has been allocated only $800,000 for the entire State.

Another point which generates great concern is the requirement for providing up to 90% of federal funding in officially designated poverty areas. We recognize that a state *can* provide 100% funding for poverty projects provided they meet the overall federal matching requirement (i.e., 30% in FY 1973). In our role as advocates, however, it seems quite proper to raise a question regarding the "matching" requirement. The notion of requiring matching grants by states or by localities goes back to the Puritan ethic which held that money given without requiring something from the recipient, would lead him into the "immoral" condition of dependency, i.e. not being willing to help himself.

One point of view on this has been that this Puritan philosophy through the extensive financial resources of the Federal Government has placed a continuing obligation on communities for an ever increasing load of financial responsibility for programs which they may have postponed had it not been for the Federal "carrott." If the majority of taxpayers and if the conscience of Congress feels that compassionate and helpful services to the mentally disabled are desirable, then it follows that equal service should be given throughout the country and that this could only be ensured to be equitable if Federal funds cover 100% of the cost.

This position is valid not only for urban inner-city areas but for rural areas as well. Otherwise, the richer states are always going to be able to make better use of the federal pot than the poorer states. As advocates for the elimination of developmental disabilities, it seems quite appropriate to question wither formulae that were perhaps appropriate in the 17th and 18th centuries are appropriate for our 20th century mobile society. Surely, adequate assistance to the developmentally disabled is more apt to help him be independent. Adequate relief enables people to lift themselves up–inadequate or minimal aid is like a slow death for a starving man.

It is agreed that our role as advocates is to press for more funds for prevention across a wide spectrum rather than have it solely the responsibility of Developmental Disabilities. The reason for including such a focus here is that nowhere are the effects of poor health services, inadequate housing and diet more apparent or more grim in their results than in the developmentally disabled. Therefore, those agencies and people involved with the developmentally disabled have a higher responsibility it seems, to advocate the inclusion of a designated responsibility for mobilizing all preventive services so as to have the greatest impact on the problem.

The paradox here is that while they may be protesting about additional money for health care and for adequate public assistance allowances, the taxpayer would save money in the end. This is often a hard point to get across because initially it is true it would cost more; but if there is not a turn around in this, then we would only be putting our fingers in the dikes and serving more and more people with developmental disabilities which could have been prevented had money and services been appropriately available. According to Mrs. Weis, "What is socially desirable is fiscally sound."

The need points to programs that will get into the home and help families with problems such as those affecting newborn infants. At Temple University Hospital in Philadelphia, for instance, over 300 babies are born each year that are identified as in trouble or "at risk."

A real program of prevention will require an adequate diet, adequate housing without lead paint, availability of comprehensive health services, better prenatal care and quality education.

These families need to be provided with good physical and occupational therapy. Good health services and comprehensive human services must be secured for these children if they are to survive. Specialized day care services are needed when they are two years old so that they have a real chance to develop into happy healthy human beings. Our major responsibility is to advocate for these children; they have received a rotten deal thus far.

Pre-conference participants stressed that a heavy emphasis be placed on programs for younger children because this is an area where we are having many problems which might otherwise go unnoticed. The whole idea is to identify and resolve developmental disabilities early, before an individual reaches adulthood. The adult problem is a critical one, and waiting lists are far too long. The fact is, however, that children do grow up, and it would be wise to detect problems at an early age as well as provide a continuing service for adults.

Many professions in the field of mental retardation opposed the inclusion of autism in the initial regulations because this disability came under "Mental Health." It is currently not included in the guidelines. Childhood autism, however, is a substantially handicapping condition and in many of its symptoms is not unlike retardation. In fact, many excellent professional facilities sometimes struggle for years to be able to look at children as children and not by diagnoses. But that time is not yet here for all of us.

Training of Personnel

A major need in providing services to developmentally disabled children in the inner city is the training of appropriate personnel to see to it that services are delivered to children and their families on a day-to-day basis. One hospital in Philadelphia, St. Christopher's Hospital for Children (SCHC), has developed a pilot Home Care Program. The program contains a Home Training segment for the training of child care workers consisting of one year of study at Temple University with training provided in three phases of 15 weeks each.

Phase I focuses on the mechanism of observation and recording. The greatest emphasis during this period of time is an extensive study of human growth and development from birth to age five. Phase II focuses on the study of human growth and development through the period of adolescence. The emphasis during this period is upon the emotional needs of children, methods of testing and evaluation. Phase III explores the nature of emotional disturbances and the significance of interplay within the family as a social unit.

The relationship of the Child Care Worker with other members of a multidisciplinary team (which includes pediatricians, psychologists, physical therapists, occupational therapists and speech therapists) was discussed during this period. There are three field experiences of 14 weeks each offered to the students. Experiences with handicapped and emotionally disturbed children are supervised by staff members of agencies such as the Pennsylvania School for Emotionally Disturbed Children and various day schools and get-set programs.

At the conclusion of the internship they are qualified as certified Child Care Workers by Temple University. Child Care Workers accompany parents on each visit to the clinic and emphasize the importance of keeping appointments. Under the supervision and direction of other members of the multidisciplinary team, a specific plan is worked out for each child. This includes short and long term training for both the child and his family. It is the role of the Child Care Worker to incorporate the family into the program. For example, should the child need special exercises for developing large muscle control the mother will be taught to carry out the exercises while the child care worker observes, instructs, and demonstrates.

As a result of the child Care Worker's involvement with the family, she can identify environmental problems which tend to retard optimal growth and development such as poor housing or inadequate care from parents. The effectiveness of the Home Care Program is apparent. During the period of January 1, 1971 to January 1, 1972, the child care workers team made a total of 1,165 home visits to 55 children and their families. Sixty percent of these children were under 2 years of age. The Home Care Training Program at SCHC has been instrumental in helping other agencies organize and develop programs in their catchment areas.

Problems of Transportation

Another problem pinpointed was that of transportation. Child Care Workers are forced to use public transportation which is a great hindrance to their work. Transportation can be an expensive item in day care programs for children who have to use two or three buses a day. Parents accompanying handicapped children experience many problems because of the special needs of these children. A cheap or free transportation system for workers, children and their families would tremendously increase the quality of services.

CENTER FOR PRESCHOOL SERVICES IN SPECIAL EDUCATION

The Center for Preschool Services in Special Education is a national demonstration program supported by the Bureau of Education for the Handicapped (Title VI), Office of Education. This program is working as a model for early detection, diagnosis and comprehensive treatment of handicapped preschool children attending federally funded preschool programs. The focus of the work is to provide immediate family aid and child services to handicapped young children through collaboration of mental health and public educational systems.

The demonstration program is set up for replication in every "neighborhood" in a city. Under the existing "right to education" mandate, immediate need exists for appropriate integration of mentally retarded, epileptic, cerebral palsied and neurologically impaired children into existing regular classrooms, or into specifically designated facilities to meet special individual needs. It is considered vital that the State Plan for the developmentally disabled view the center model as a viable method by which both the educational and therapeutic needs of handicapped young children will be served. Unlike a number of individual programs in this area which often focus on one or another specific aspect of services for the defined population (e.g., training of child care personnel, support and guidance for parents of handicapped, etc.) the center concept includes a totally integrated approach to the identification and remediation of handicaps at the point when the young child enters the classroom situation.

The accompanying integrated plan in special services for preschool children describes a method by which an inner city can move in the direction of providing appropriate services to all handicapped preschool children. Under the provisions of the Developmental Disabilities Act, a realistic approach would be to provide the funding necessary to the "linked" units in each service area. This in no way needs be the total responsibility of any given agency, but rather the shared responsibility of Mental Health and Mental Retardation, Public Education and the Developmental Disabilities Planning and Advisory Council.

Integrated Plan for Special Services for Preschool Children

1. Screening

All preschool head teachers and supervisors in the five catchment areas of the city would be trained in the administration of a screening instrument (e.g., Denver Developmental Screening Test).

a) Numbers of teachers and supervisors–approximately 225.

b) Training time (time out of classroom) one day per catchment area.

2. Disposition

a) Group I–Remain in regular classrooms; within norm range on D.D.S.T.

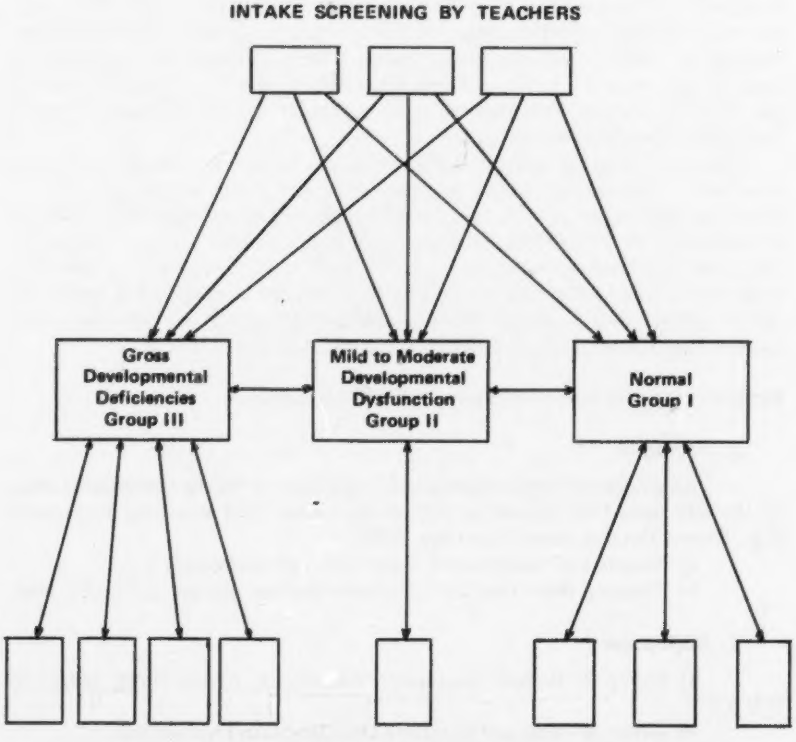
b) Group II–Mild and Moderate Deficiencies in Dysfunction.

Referral to ½ day preschool diagnostic/therapeutic center for appropriate diagnosis, intervention and placement.

c) Group III–Gross Developmental Deficiencies. Referral to Day Care retardation centers for appropriate diagnosis, intervention and placement.

[NOTE: The arrows in the accompanying diagram refer to the flexibility of movements among the various classrooms or settings for a child studied and found to be a mentally deficient child and who could probably profit from a normal day care setting with a part-time therapeutic setting (group II units). The child could be entered into a local regular day care setting with the referral center working in cooperation with him.]

Another example might be a child who is viewed as developmentally "normal" but is showing real difficulties in his peer relationships in the classroom. The regular teacher may refer the child to the ½ day diagnostic/referral classroom while he remains within the regular classroom setting.


INTAKE SCREENING BY TEACHERS
Gross Developmental Deficiencies Group III
Mild to Moderate Developmental Dysfunction Group II
Normal Group I
Retardation Day Care Centers
Diagnostic/Therapeutic Preschool Centers Classroom
Regular Classrooms

MODEL FOR EACH CATCHMENT AREA

NATIONAL CONFERENCE WORKSHOP SUMMARY

Participants who attended the conference workshop on Services to the Developmental Disabled Within the Inner City unanimously agreed with the major contention of the background paper that more emphasis, concern, energy and resources must be brought to bear on the problems of prevention rather than a continuation of the treatment of the symptoms. Perhaps the volunteers and professionals in the field of developmental disabilities can be the catalyst for bringing these resources into play.

There is a need for a blue print of services that can be made available at the community level. There is a need for a list of basic services so that service delivery no longer becomes available on a hit or miss basis. There is a need for an existing service to be checked and evaluated to determine gaps. There is need for trained administrative personnel to administer and coordinate the constellation of services required.

According to Dr. Frederick Green, Associate Chief for the Children's Bureau, who was one of the national conference workshop participants,

> There is a normal sequence before a program can be put into place, whether it is in the inner city or whether it is in the suburbs. That sequence would seem to me to be not only the perception of need which we have constantly established, and the dismal facts that we have in the inner city; but also there should be a period of conceptualizing and defining options and alternatives before programs are initiated.
>
> A small program that has been well conceptualized may add a great deal to our knowledge as compared to a larger program that is simply reacting to a need without adequate thought given to a variety of consequences. It just seems that we have to think of our actions at two levels.
>
> Some individuals may not be motivated to use services so that part of the conceptualizing of a program should be the motivative factors which should be brought to bear. An institution should have built into it an outreach unit so that they do not always expect individuals to come to them for services. You are often dealing with people who are not motivated to preventive care but rather motivated to episodic care and therapeutic care so that they will only come to a facility when a child has a sore throat. They cannot afford to take a day off simply to have a routine checkup.
>
> When conceptualizing programs preventive care must be considered along with the therapeutic care aspect at the point of entrance of the individual into the health care system. If it is an emergency room, which happens to be in most instances the single largest source of medical care for many people in the inner city, then these programs should develop linkages in some way at the point of entrance so that a child does not come in simply to get a shot of penicillin for a sore throat and then disappear out into that vast population not to be seen again until another chief illness occurs. Therefore, it just seems logical that entrance into the health care system would not only facilitate therapeutic medical care but also the beginning and then the identification and outreach for further treatment of children with a variety of developmental disabilities.

Although we have talked about identifying the problems some of us may have difficulties with the methods that are used. Who does the identifying? What instruments are used to identify? Are the instruments appropriate for the individuals who are being identified? It goes back to the whole issue of labeling and many of us take a very dim view of the way some children are identified as functionally retarded or dull on the basis of certain instruments that are utilized in a population where cultural bias can be built in.

John Throne from the University of Kansas, pointed out that the definition of developmental disability has been a rather controversial issue particularly in regard to the section on the neurologically handicapped which produces a different image in the minds of different people, particularly in regards to inner city needs as opposed to the specifics of prevention. As we know the great bulk of the inner city population who are under functioning are not that way because they are neurologically disabled but because of the lack of opportunity to develop normally. What are we going to do about that, and what kinds of monies will be available under the Developmentally Disabilities Act as a means to tackle this issue? This is a matter of great concern.

Leverdia Roach, of the Social and Rehabilitation Service, summarized the workshop by stating

> We must consider seriously our place in time and history. We would like to be all things to all people; that's ideal. The purpose of this act was to get away from categorization. We have talked about the mentally retarded; the act addresses itself to the mentally retarded, the epileptic, and the cerebral palsied. It goes on to mention other neurologically handicapping conditions which resemble or require the same or similar treatment. We are concerned with a population or with people in our country who have for many years fallen through the gaps or who have not been served because of the complexity or the multiplicity of their handicaps. With the group that we are striving to serve, often this does not mean creating a new service, it means calling on agencies that already have authorizations for providing services to do that for which they are authorized.

RECOMMENDATIONS

As a result of the discussions on services to the developmentally disabled which took place at the preconference meetings held in Philadelphia and at the national conference workshops held in Washington, the following are submitted for consideration. It is recommended that:

1. the Hahnemann catchment area proposal be given serious consideration for funding;

2. future conferences sponsored by the National Advisory Council on Services and Facilities for the Developmentally Disabled be advertised widely so that agencies directly involved in providing services to developmentally disabled children can send representatives and have an opportunity to participate;

3. the "matching" requirement be eliminated and federal funding cover 100% of the costs;

4. developmental disabilities programs include a designated responsibility for mobilizing all preventive services so as to have the greatest impact on the problem;

5. autism be defined as a developmental disability because it is a substantially handicapping condition and many of its symptoms are not unlike retardation;

6. a cheap or free transportation system be provided for workers and their families which would tremendously increase the quality and availability of services;

7. the center for Preschool Services in Special Education be seriously considered by the Developmental Disabilities Advisory Council as a viable method by which both the educational and therapeutic needs of handicapped young children will be served.

8. a "blueprint" or list of basic services be made available at the community level so that service delivery no longer becomes available on a hit or miss basis. Existing services should be checked and evaluated to determine gaps;

9. programs be conceptualized and options or alternatives defined before programs are initiated;

10. outreach programs be designed so that the developmentally disabled are identified on their entrance into the health care delivery system. This approach would not only facilitate therapeutic medical care but also provide a point of identification for further treatment of children with a variety of developmental disabilities.

REFERENCES AND NOTES

The resource and background information contained in this paper were obtained from the following sources:

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3. William J. Cohen, Ph.D., Associate Director, The Hahnemann Catchment Area, A Demonstration Program.

4. Jack L. Boyle, Director, Pennsylvania Developmental Disabilities Planning and Advisory Council.

5. Catherine D. Weis, Director, Mental Retardation Services North Central Philadelphia Community Mental Health/Mental Retardation Center.

6. Rebecca Thomas, St. Christopher's Hospital for Children.

7. Louise Sandler, Ph.D., Project Director, Center for Pre-school Services in Special Education.

8. Dr. Frederick Green, Associate Chief, Children's Bureau.

9. John Throne, University of Kansas.

10. Laverdia Roach, Social and Rehabilitation Services.

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Reaching the Developmentally Disabled Among Special Disadvantaged Groups

Armando Sanchez

> "The Developmental Disabilities Law requires the states to exercise outreach and to give technical and financial assistance to areas of special disadvantaged. This is interpreted not merely in terms of economic disadvantaged, but also in terms of cultural differences . . . there is still a very considerable need for council members and their staffs to understand and locate the channels through which they may secure participation of the leaders of specific cultural groups and the families belonging to these groups who have handicapped people, in identifying their own needs and asserting their own concerns about how these needs may be met."[1]

This is the essence of the assignment given to me. It reflects the increasing national concern with the provision of comprehensive health services, or lack of them, as it affects the "quality of life" of various ethnic minorities in this country. Existing trends to improve the quality of life through more effective delivery of health services to indigenous minority groups now include use of para-professionals, development of neighborhood health centers and increased minority consumer participation on local health agency advisory councils. While these are laudable efforts, I maintain that they represent only a partial band aid solution to the more serious and pervasive health dilemma in which Chicanos and other minority groups find themselves—denial of a healthy living environment by social class circumstances and professional prejudice in health care.

En precis,

1. An Anglo middle class syndrome permeates health service programs with little empathy for and considerable confusion about Chicanos and other minorities;

2. The premise in choosing methods of providing health services are often ineffective because they are at variance with Chicano and other minority social and community organization structures.

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[1] Communication of assignment from the Conference Staff.

Statistically the total U.S. minority group population is 34.8 million or 17.7 percent of the U.S. population of 203.2 million, according to the 1970 census. Out of the 34.8 million, blacks represent 22.6 million, Spanish-speaking 9.3 million, American Indians 0.8, 1.5 million Asians, and .6 other minority groups.

Very recently a document titled "Special Survey of Minority Group Needs With Special Reference to the Role of Grass Roots Minority Organizations on the Delivery of Services" reached my desk.[2] The document presents the following four goals:

1. "To examine the current service delivery system for VR and DD population and determine if such a system meets the service needs of disabled minorities."

2. "Identification of unique problems of minority groups in the delivery of services."

3. "Identification of grass roots organizations in the community, particularly in the barrios and ghettos providing services to the disabled minority clients and of those with potential for delivery of services."

4. "To demonstrate the feasibility and effectiveness of using grass roots minority organizations in the delivery of services."

With respect to goal 1, this information is already available.

Goal 1

This information is already known to the Minority Studies Program when they report that only 4.7 percent of Spanish surnames are rehabilitated yet the Spanish surnamed make up 6.11 percent of the country's total population.

Goal 2

The problem of minority groups can best be articulated by members of that minority group. There is little assurance that RSA personnel has the appropriate personnel to check on their own cultural bias in identifying problems of another group.

Goal 3

(1) There are relatively few grass-roots organizations presently providing rehabilitation services, (2) RSA probably is not in a position to identify those grass-roots organizations with the potential to deliver services, and (3) the potential of an organization may be judged by RSA solely in "accounting" terms without sufficient value given the benefits as perceived by minority persons themselves.

Goal 4

The feasibility of minority organizations seems to be a value judgment depending on the variable to be used. A better goal might be: (1) to identify grass-roots organizations with interest in the rehabilitation service area, (2) develop training programs to help minority staff to become more knowledgeable about the rehabilitation process, and (3) facilitate management and project administration.

The document identifies two issues: (1) the determination and identification of VR and DD needs of minority groups and the implementation of programs tailored to their needs; and (2) assurance that minority groups are getting a fair share of RSA's market basket (overall VR and DD services).

It seems to me that the writers of the document not only present superficial issues but also beg the question by posing two issues which detract from the real issues.

The writers of this proposal approach the problem by suggesting that the present white, middle-class professional will judge the adequacy (feasibility and the success) of minority grass-roots organizations to provide rehabilitation services. The alternative to the establishment agency providing services is to permit "grass-roots organizations to provide services in special cases" and to consider "the possible use of local minority organizations of services *in certain cases.*"

The factor of race relations is not at all considered or admitted nor is the possibility of institutional racism acknowledged in any way.

The basic structure of the Rehabilitation Service Administration is not addressed. Furthermore, no mention is made of its extremely low number of ethnic minority employees at all levels and the poor record it shows in recruiting and training ethnic minority persons to become professionals in this field; nor is there any reference to the under-representation of minority persons in the statistics listing persons being successfully rehabilitated.

At the present time there have been few evaluations conducted which question the basic assumption of the knowledge base in the "Rehabilitation Process," or of the basic curriculum taught in Graduate Departments of Rehabilitation which may or may not reflect only white, middle-class values and mores in human relationships. The degree of estrangement a minority person may feel in an anglo dominated agency probably can best be documented by minority researchers. It would seem these are basic questions in making rehabilitation services more available and more effective in relating to minority clients.

The basic presumption on the part of RSA in making this proposal is that minority groups seeking the expansion, or in many cases, the initiation of services to their constituencies by SRS must be examined and their role defined in this endeavor by the very institution presently not responding to their needs. It appears RSA seeks extra funds to relate to minority groups rather than commit program funds they now have for this purpose. It is our understanding that the Minority Studies Program, through the ethnic planning projects presently funded, was to assist SRS, including RSA, to examine and re-define the policies and procedures of SRS agencies in their delivery of services to minority populations.

Robert R. Merton in *Social Theory and Social Structure,* in introducing the concept of latent functions, states: "To seek social change, without due recognition of the manifest and latent functions performed by the social organization undergoing change, is to indulge in social ritual rather than social engineering (pages 51, 63, 66, 68 of Merton(2)).

Merton defined latent functions as these objective consequences of a social practice or belief contributing to the adjustment or adaptation of a system

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[2] HEW-SRS document.

which are neither intended nor recognized (Merton, pg. 81(2)).

In some circumstances such functions remain unrecognized as related to the basic and fundamental issue of adequate resources and the right to utilize those resources to exercise self-determination. The problems may be defined by agencies in a way which makes their services appear the key to the solution and which expands their services, while leaving untouched more important aspects of the mainsystem which can and do continue to produce poverty and dependency. In the process, attention becomes shifted from the characteristics of the mainsystem to the deficiencies of minorities, a process aptly described by Ryan as "blaming the victim (Ryan(4)). Attention becomes deflected from the large issues. It is much easier to confront the minorities as disadvantaged groups demanding better social services than as determined revolutionaries demanding social justice.

The search by minorities for new vehicles with which to apply pressure to governmental institutions has traveled the spectrum of political activity. But whether reformist or radical in approach, minority groups seeking basic societal changes have all seen as a central problem the need for increasing the access to resources which the minority people of this country have historically been denied. Coupled with this need for resources is the equally important need of political control. What little voice minorities have had in voicing their position on policies which have affected them has been in retrospect related to decisions which others not of the minority community have made. Even granted that some "imposed" decisions have been more benevolent than others, the basic right of self determination has not been allowed the minority groups. The decision-making process has been administered by a complex system of institutions which has never included minorities to any appreciable extent, if at all (Dornhoff(1)). Thus, the lack of resources and exclusion from the policy-making process has kept minorities in a vicious circle of almost total dependency on a system of government in a society in which they function, but of which they are not a part.

Let me consider a specific minority group; namely, Chicanos, for although the title of this paper does include all minority groups as the target group, I will not presume to speak for all minority groups.

Moustafa and Weiss noted that there are "glaring deficiencies of information on Chicano mortality rates, morbidity characteristics, mental illness and health attitudes and practices. With rare exception the comparatively limited sociological and anthropological literature touching upon health issues does little justice to the Chicano. Consequently, the conclusions and data based on such limited research on Chicanos are often used as empirical evidence upon which human service agency policies and programs are based. Chicano communities are generally regarded as a variant microcosm of the dominant society interrelating with external institutional structures. From this premise numerous decisions are made on how to serve Chicano communities by a variety of human service agencies. The disadvantage of this concept is that Chicanos are viewed as acting out roles at a level which confronts their immediate environment and circumstance without regard to the legitimacy or origins of the interactions. Chicanos are viewed as differential people in a common social system of which they may or may not be a part. All too often I have observed various health service agencies seeking out Chicanos' "community" and "consumer" participation solely for the purpose of legitimizing their programs with little regard for integration of their services into the existing community structure.

I would suggest to professionals that there is not a single Chicano community but rather there are divergent and heterogeneous communities definable primarily by internal social interaction and interdependence more than by physical or Anglo institutional considerations. I further propose that the notion of Chicano communities is a multi-variant concept denoting an ethnic collectivity sharing common elements of the heterogeneous culture in a dynamically structured society. The issue here is that Chicanos and the concept of community should be viewed interdependently rather than separately.

To be effective, programs must reflect a Chicano community orientation, a personalized system of service, and capitalize on the existing systems. Sanches states that the very notion of providing symptom oriented services must be redefined and health programs redesigned within the framework of the Chicano community:

> The health of an individual and community does not exist in a vacuum; rather, it is related not only to the total environment but also to other individuals and the network of interrelationships that give life to the total community . . . Hence the well being of an individual and community must be studied from within the barrio with its complex network of relationships. It must be kept in mind that the barrio is a social institution which affects the lives of those who live in it. (Moustafa & Weiss(3)).

To my knowledge there are no service programs which reflect an understanding of, or are integrated into the Chicano community life styles. Rather, I have found service programs to reflect an Anglo middle class mentality–the programs are defined within a framework of the medical and psychoanalytic models and are premised on the sociological assumption of assimilation and the political philosophy of colonialism.

Nonetheless, I offer the following recommendations:

1. Serious actions should be taken to recruit and train Chicanos to work with the developmentally disabled.
2. Graduate Departments of Rehabilitation should be modified to reflect existing realities and new courses regarding "community health" be introduced;
3. Programs should be redesigned to recognize and incorporate the diverse cultural, linguistic and ethnic elements appropriate to the client population;
4. Chicanos should be recruited as paid consultants to serve on policy and grant approval boards;
5. Professionals should educate themselves concerning Chicano needs and community dynamics;
6. A comprehensive Chicano needs study to be conducted by Chicanos should be commissioned.

The refusal to implement necessary action to meet minority needs is to perpetuate the problem, invite controversy and increase the credibility gap professionals suffer in Chicano communities.

I quite agree with Dr. Skillicorn(6) that "C-Care" must be developed in minority communities:

Congenial care—personal, courteous, respectful care;
Convenient care—accessibility and minimal waiting;
Complete care—not incomplete, assembly-line care;
Consistent care—familiar, predictable, continuous care; and,
Compassionate care—concerned, caring care.

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WORKSHOP DISCUSSION

In the case of minorities, it is equally important to deal with both consumers–to train and involve parents of developmentally disabled persons–and professionals. Professionals control, to a large extent, the resources; minorities need professionals from their own groups. At this point in time minorities have a severe shortage of professional manpower. Hence, a priority needs to be placed on training of minority professionals, for control of and/or access to resources is a prerequisite to provision of services to minorities.

The troubles which disadvantaged and deprived individuals and groups experience cover every area physical, medical, economic, educational, social and political. Anglos tend not to relate to all these factors because there is the racist's need not to see them.

The attitudes we as minorities have developed are in reaction to the attitudes and abuses perpetrated by the majority–and they rather than we need to change.

The concept of "difference" in all of its definitions, denote minorities as inferior and not worthy of respect. If the "normal" person can't be respected, what happens to the "retarded," "handicapped," etc.

One point I would stress is that enough studies have already been done, defining the needs of Black and Chicano communities. Rather than promote more monies for more studies, why not provide monies to Black and Chicano communities so that they can begin to attempt to *handle* not solve some of these well-known, overly-documented problem areas? "Human services" instead of "special services" should be demanded, and anything less is unacceptable.

In the area of training, before we start recruiting and training Chicanos to work with Chicanos, let us be assured that there is a program that reflects the linguistic and cultural characteristics of such a population. Moreover, when services are made available, there must be some assurance that they are available at times convenient to the consumer.

The dual responsibility born by service agencies at this time is to reach out to minority communities and make appropriate changes in their delivery system so that existing services are utilized; additionally, conscious efforts must be made to recruit and train minority personnel.

Restrictions and constraints imposed by implementation of local policy and/or State and Federal guidelines must be eliminated. Completed studies, massive reporting, innumerable recommendations have been submitted and nothing results. Too many studies have been made of "minority problems" but little action has followed.

Summarily, early identification of persons with disability needs to be made (case finding). Secondly, a determination regarding who should get diagnostic services needs to be made. Thirdly, treatment appropriate to the individual must be given by a knowledgeable and skillful doctor within the context of the individual's cultural life style.

Technical competency and community understanding are needed in order to render services to the developmentally disabled. Moreover, social problems must be overcome before medical and psychological problems can be solved to any appreciable extent.

Special Problems and Special Aids in Resolving Special Needs in Rural Areas

James MacDonald Watson, M.D.

The workshop on the special needs in rural areas was conducted twice with strong participation by many, both from the floor and in each of the two panels. The final report, therefore, includes the original text of the topic as well as the largely unacknowledged contributions of many others. Common to each of the workshops was the understanding that no state or region had either unique problems or unique solutions, and that no one was able to provide all the answers. There was also a common agreement probably best expressed by Thomas Scheninost who made two very strong points that: (1) the developmental disabilities needed a stronger voice representing rural and remote areas to re-emphasize that the needs of urban and rural areas are not the same, and (2) that the developmental disabilities legislation must be continued, observing that the "concept of this legislation has done more good than any other Federal program in the generation of services and in the coordination of services."

The title of the workshop perhaps overstates by repetition the problem of "special," but there is no doubt that rural areas have certain aggravated or heavily weighted needs for services to their developmentally disabled. Reflect again on the famous list of 16 services that Public Law 91-517 was designed to include: it starts with diagnosis, evaluation, treatment, . . . information, referral, follow-along, and finally, transportation. For each of these, weigh the impact of geographic remoteness and sparcity of population. There is no service that is not immediately compromised; transportation looms ever larger since it becomes the means of procuring any of the rest of the services. Reflect also that 54 million Americans live in what are considered rural and/or remote areas, that most rural areas enjoy a far lower general level of income than the population at large, and that each of the states which considers itself to be predominantly rural is funded at near-minimum levels in all Federal programs in which allocations are based upon population. A real penalty accrues to the area that is largely rural, because such a biased assignment of dollars penalizes the program that must spend a disproportionate amount in an effort to deliver the services because of the scattered and remote nature of its clientele, many of whom are already impoverished. Just to further muddy the waters, I should like to consider two more potential services. None of the specific services can be provided without *case-finding*. This is, of course, the first step toward diagnosis, hence I consider it separately, and I suppose that it might be called detection or epidemiology. Secondly, but distinctly corollary to case-finding is the field of *"public" education* (as opposed to "client" education). I am not immediately aware of data regarding mental retardation or cerebral palsy, but there is a well-documented analysis of "public attitudes" toward epilepsy (Caveness, Merritt, and Gallup) that speaks volumes. These studies record slowly improving, evolving attitudes toward this condition that are partly the result of a not-terribly-well-structured educational thrust. The data also points to a hardcore of opposition and ignorance that will probably never disappear but can yield further through organization of effort. The point, of course, is that detection and all the rest in rural areas is extravagantly costly in money and time, but it is in the "country" that the most miasmic attitudes toward epilepsy (and, I am confident, toward mental retardation and cerebral palsy) are to be found. Hence, the two concepts of *casefinding* and *public education* are doubly compromised due to both lack of funds and to prevailing attitudes.

In Oregon, which is fundamentally rural in nature but with problems that are not unique and nowhere near as impressive (oppressive?) as those of some of our fellow participants, well over three-quarters of the population of 2 million lives in a narrow strip of land, inland from the Pacific, separated from it by a soggy chain of mountains. The eastern side of the populous strip is separated from three-quarters of the state's total land area by another chain of mountains. "Coastal" people and "eastern" people have really only a difference between their feet (wet or dry). They are otherwise indistinguishable in their remoteness from service and often even their lack of knowledge of a need for service and/or a place to start. An anecdote may illustrate the point. A patient that I recently saw from the high desert mountain country of eastern Oregon, in his 60's, was one day in the local "country" doctor's office for nothing special, and thereupon had a major convulsive seizure. The doctor, without further ado, literally rushed him to me by air, to the big city (air ambulance, 300 miles), but failed to send along the spouse. I couldn't find anything much to go on, and three days later the wife appeared (by oxcart?), puzzled by what all the fuss was about. I explained what the doctor had described and its apparent ominous portent ("a grand mal seizure," I said) and she said, "Oh, is that what that is"; whereupon I said, "Is what 'what that is,' " and she said, "Them." "Them," I said, "you mean he has had 'them' before?" "Well, yes, for at least the last 39 years that I have been married to him. Never knew what they were. Is it bad?" Well, it is clear that this mountain family had taken this in stride. The patient had worked on, in spite of many seizures while ranching, and without outside witnesses, made little of it and apparently had not really needed to do otherwise. Not so his children. It turns out on close questioning that both of his boys, now adults, had had seizures in their childhood and one is still subject to them occasionally. Neither of them had had anywhere near the same philosophic approach toward his illness, mostly because of the social, economic, and educational pressures of growing up with a disorder that distinguished them as different from their peers. The father may have been able to deal with his situation in such a way as to effectively "go it alone," but one knows that there are a good many examples of potential clients forced by geography, culture, etc., into such circumstances that don't fare so well.

At this juncture, a comment about that physician is probably worthwhile. He certainly acted with dispatch in seeting to it that the patient was forwarded to a diagnostic center. The air transportation and its appurtenances cost a pretty penny. It is true that there are not facilities for more-or-less "first-class" neurologic diagnosis much closer to that physician, but it is also clear that the patient need not have made the journey. The practical facts are, as viewed by most of us who routinely treat epilepsy, that most such problems can be handled on a much more local basis until or unless some greater need for more fancy medical evaluation is justified. As a matter of fact, the lesson of a reasonably practical and simple approach to epilepsy had been the point upon which I had last met that particular physician. I, as a lecturer in a travelling "circuit" course, toured the Northwestern region under the Regional Medical Program for two years, bringing modern concepts of neurological diagnosis to the hinterlands. This particular physician, among others, and I had sat for three hours and had quite specifically discussed the differential management of, among other things, convulsive disorders. Somewhere I failed to transmit the message that I thought I was there to give, or the physician failed to receive it, or it had not remained with him long enough, because the end result was that the physician faced with the epileptic problem immediately overreacted, to say the least, and thereby burdened the whole of the medical referral system at a far larger expenditure both in money and time and transportation than really was appropriate. It seems to be clear that the effort at the grassroots is commendable, and probably carried a message that was wise, but that particular approach obviously has its holes and requires polishing and supplementation with other methods of bringing a simple educational message to those who might best use it.

Responding to our geographic needs as well as an appalling lack of information, Oregon's DDSA council initially undertock to foster proposals, originating really with mental retardation programs, and funded the establishment of two fixed points of referral, or to be more precise, service coordinators (since "fixed" they were not). (In South Dakota these individuals and their programs are known as resource coordinators.) Both of the programs that we initially funded were to cover coastal areas with sparse urbanization, two counties each. One coordinator first had to beat the bushes just to make herself known, to locate services and resources, while the other with some greater background already available literally snooped for clients for distribution to known services. The usefulness of each program has grown so that provision for follow-along services was required in later funding. Because of the success of these two pilot studies, there are now very well advanced plans for a dozen more DDSA supported or coordinated similar projects. The happy feature is that, although the Developmental Disabilities Council was able to get these programs started, the state was able to include them in its provisional budget, thus freeing Developmental Disabilities money for further innovation. Oregon is now wholeheartedly in the business of service and resource coordination. Its primary purpose can often be case-detection and reporting (my added service) leading to implementation of the rest of the services. This has probably been of more pleasure to those of us who represent epilepsy and/or cerebral palsy on the Council than it has been to those people in mental retardation, because of the case detection that has been lacking in both of those areas. Some of our service coordinators will operate out of multi-service centers in cities and towns with many kinds of immediate advice and guidance, but the bulk of them will continue to operate in rural areas, remote from either the University Affiliated Facility or the clinic, remote from the State capitol and centers of population, ofttimes working out of the trunk of a Chevrolet with a roadmap, a flashlight, and a set of tire chains. So far as *public education* is concerned, the coordinator is obviously invaluable.

Diagnosis and evaluation is often tough to provide once detection has occurred, as we all know. Oregon is lucky, in a sense, because it has two University Affiliated Facilities (UAF). All, however, are in that rather narrow strip, hence transportation and housing are costly items. We have given, as have other states, consideration to traveling clinics, and it seems inevitable that this occur in some form. We also discovered that in order to establish such a clinic and minimally staff it, fully half or more of our meager developmental disabilities allotment would have to be expended immediately; as a consequence the concept was put on a back burner.

Other states have functioning clinics that travel, but I would point out that sometimes much of the contact can and does take place over television and telephone circuits, so that maybe what travels needn't be the "clinic" but an electronic interface operated by highly skilled paramedic, paraprofessional types (para-saint, I also expect). One should be reminded of the remarkable work being done in the Southwest and in Colorado by Doctor Bransford and his group utilizing two-way audio and video transmission mechanisms via, of all things, a satellite. The principal concept is to supply immediate, indeed "now," two-way interaction into a potential of 300 sites in eight states. The Federation of Rocky Mountain States program, once it gets into operation, could conceivably supply what many of our states cannot provide. Again, to use the example of Oregon, which is relatively well-off, there are 27 neurologists in the state, but none of them practice outside the narrow strip of populous counties. Of the 36 counties, however, none is without television, cable or otherwise. With the implementation of a program of two-way communication, such as Bransford's program could supply if the area were included in the surveillance pattern of the satellite, an eventual program of contact with remote areas would be operating without the experts ever leaving their desks.

Another concept that is very exciting and worthy of a good deal of attention would be the use of television cassettes as a home-training device, especially in rural areas. Shortwave radio has been used for a long time in remote areas, such as Alaska, but nowadays with the heavy emphasis on cable television and the immediate access of videotape in cassette form, the concept of supplying follow-along home training, one-to-one teaching programs, etc., by using this means, which doesn't necessarily require a satellite but simply electricity, is fairly staggering.

Thus, the day may come when the frustrations we presently experience in Oregon because of the remoteness of the clientele from our two bricks-and-mortar installations known as University Affiliated Facilities will no longer be the case. These two agencies plus other smaller and less grand operations, perhaps operating in connection with one of our spread of community colleges or some expansion of a particular mental health clinic, could easily supply the immediate source required for transmission to the individual and his family or advocate. Oregon has been able to innovate a program of in-home training advice, counsel, and follow-along, using the parent and family as the trainers rather than attempting to parcel out the too easily diffused services of traveling therapists and relying only on their infrequent contributions.

The Developmental Disabilities Program has been able to fund at least one project in which the community colleges have undertaken training programs, not only for parents who can then return home, but for aides who can, in turn, help provide more solid forms of local assistance. Since our community colleges are like those in most states, perforce in some rather desirable rural or remote locations at the whim of the State Legislature, their capacity for community service of this kind is perhaps untested, but it seems potentially great.

To a small extent, training programs in the State are already in operation, mandated by the fact that the creation of the service coordinator or resource coordinator position has necessitated the engagement of individuals whose background, particularly regarding cerebral palsy and epilepsy, is meager and whose knowledge of the availability of state services, etc., is only superficial. The training program necessary to generate materials and background for these individuals has, in turn, indicated the need for further activity, especially integrating other state agencies such as Vocational Rehabilitation, Welfare, and Education.

Some attention must be directed to the concept of the "centers of excellence." Local, area, or even state, diagnostic and evaluation facilities notwithstanding, there is a clear need for national, perhaps actually HEW regional centers of genuine excellence. The voluntary epilepsy movement has pursued this objective for several years but obviously it can be easily expanded to the field of the developmentally disabled and, better still, enlarged to the concept of the "substantially handicapped." Something like twelve to eighteen facilities appropriately placed throughout the United States (are you listening, Alaska?) with provision for all the corollary services, to maximize training, research, epidemiology, etc., are sorely needed especially for those of our population who do not live in the shadow of our present institutions. (Indeed living across the street from some of them is not guarantee of appropriate service. Ask the clients!) The concept of multi-state regional facility development, generated probably through HEW, might easily overcome some of the natural barriers of funding that is restricted to population and restricted also by the relative poverty of some of our areas. This is part of a concept that was originally used by the Johnson Administration in the development of programs for cancer, stroke, and heart disease, but which never quite got off the ground. Epilepsy has, as have some other categorical disciplines, continued to try to generate activity in this line, but it has not been forthcoming.

Toward the end of the second workshop, a completely unprogrammed and unrehearsed but marvelous interchange developed. The colloquy really struck at the essence of the problems of those people in remote areas. The writer had initially taken the floor to discuss the problems, as he saw them, of those in Oregon who are relatively deprived of both funds and services on the basis of sparse population and geographic remoteness. Each time he made a point, his colleague, Mr. Scheinost, representing an even more rural and even more impoverished and even more problem-ridden area, namely South Dakota, was able to intercede with a point that was not so much a putdown for Oregon as a positive score for South Dakota. With no game-plan at all, however, after listening to the relative misery of these two states, and to their not too innovative and exciting methods of trying to solve problems, one of the listeners in the group, the representative from Alaska, rose to observe that Oregon and South Dakota, as well as most of those others whom she had heard about during that day, really had nothing to worry about at all. She then recounted examples of 900-1000 mile trips by air to seek medical assistance, thereby making 300 miles look rather pale. She recounted problems of languages and culture, multiplied five times over, each of them requiring, or course, a different approach to the delivery of services. She recounted the absolute despair that one faces trying to make a sparsity of dollars cover the geographic vastness of Alaska with the remoteness of much of its population and the near-inaccessibility of some of its territory. Frankly, Mrs. Mothershead made a remarkable impression upon the group and had there *been* a "game" she would clearly have carried the day, had it not been for yet another voice. A gentleman rose from the back of the room and quite graciously thanked the speakers for their program, congratulated all those who had spoken on the *urban* nature of their problems, which of course generated some perplexity about whether or not the man knew the difference between urban and rural. The question was immediately answered when he announced his home as Samoa, and explained that he was the not terribly proud recipient of a total of, then, $15,000 in Federal funding to generate some kind of program, as well as a Council, to cover the 200,000 individuals, most of whom are not even citizens but who are considered Nationals, who are scattered over thousands of miles of ocean waste. He noted that there was about 36 miles of road in order to try to deal with these problems.

If a moral attaches to this tale, it is surely that someone is always worse off then oneself. If an action item is to be generated from it, we need write a real game plan for achieving parity, not penalty, for our rurality.

There is a final comment to make. Oregon has made certain forward steps in implementing the developmental disabilities concept. Probably, by comparison with other areas, it has moved further and faster than most. This is not accidental; it has occurred through a mechanism that is to be recommended for consideration as a "natural." The original authorization for Developmental Disabilities implementation in Oregon was an executive order by the Governor requesting that planning and policy development for the plan and its implementation rest in the hands of the State agency known as Comprehensive Health

Planning, but a service organization. The order further specified that the administration of specific grants and the evaluation thereof, and indeed the generation thereof, was in the hands of the State Mental Retardation Services. This coalition of two State agencies, an unusual one, was joined in a solid and functioning coalition of interests of the three voluntary health agencies that are concerned with this particular legislation. The Epilepsy League of Oregon, the United Cerebral Palsy Association of Oregon, and the Oregon Association for Retarded Children soon joined into an active merger of interests and an active participation for the greater good of the whole concept. These five agencies, two State and three private, joined by other state agencies, as well as pure consumers, comprise the State Council. They have succeeded in maintaining, in large part, the atmosphere of cooperation and congeniality that I am confident reflects success. Most recently there have developed regional, if you will, "mini-councils," that are starting to generate suggestions for policy and priority from what is truly the grassroots. This may very well prove to be the most potent weapon of all because it finally succeeds in giving the rural area a podium from which to present its own point of view.

Thoughtful cooperation has brought us a long way. I commend that spirit to us all.

Part IV
Utilizing Other Federal Resources

Editor's Notes

One of the unique features of the Developmental Disabilities legislation is its emphasis on making more effective use of a wide range of other funding resources. Unlike most other targeted federal legislation, the Act takes cognizance of the fact that other funding sources must be involved if the needs of all developmentally disabled persons are to be met in an effective and efficient manner.

This emphasis on the catalytic role of the DDSA program is built into the legislation. States are required to describe in their state plans the quality, extent and scope of services provided to developmentally disabled persons under nine specified federal-state grant programs. The Act also specifies that DDSA funds must be used to supplement support from other federal and non-federal sources.

Taken together these two provisions emphasize the importance of interdigitating DDSA planning and programming with the activities of other programs which have a role to play in preventing developmental disabilities and serving DD clients.

In developing the program for the November meeting, the Conference planners were acutely aware of the need to assist state council members and staff in understanding and taking advantage of the options open to the developmentally disabled under the nine programs specified in the Act. To fulfill this purpose, a series of eight papers was commissioned dealing with the role of various federally funded programs in meeting the needs of the developmentally disabled.

The authors were selected on the basis of their intimate knowledge of the operation of the particular program. Some were key staff members of the administrating federal agency; others were employed outside of government in various capacities; but, in any event, all were thoroughly familiar with the "ins and outs" of the program's operation.

The major features of one of the federal government's oldest grant-in-aid programs—the Vocational Rehabilitation program—is sketched out in a paper by Emily M. Lamborn. She stresses the recent history of the Act and how VR services have been adapted to meet the needs of developmentally disabled clients. Noting the sharp upturn in the number of developmentally disabled clients rehabilitated since 1950, she explains how state rehabilitation agencies go about serving the DD population through the basic federal-state program as well as a variety of supportive activities (construction of facilities, planning, research and training). Mrs. Lamborn closes with an analysis of some of the implications pending rehabilitation legislation might have for the developmentally disabled. Rudolf P. Hormuth describes the services offered to the developmentally disabled through the Maternal and Child Health and Crippled Children's programs. In addition to reviewing the types and quantity of preventive and clinical services available through these two formula grant programs, he also delineates the ways in which the health care project grant programs funded by HEW impact on the lives of the developmentally disabled.

Finally, the author points out the important role HEW's Maternal and Child Health Service has played in developing and supporting university-affiliated facilities for the mentally retarded and remarks briefly on MCHS's research and international activities.

Medical Assistance (Medicaid) is one federal program which is sometimes overlooked despite its growing fiscal implications for those afflicted with developmental disabilities. Richard L. Humphrey's cogent analysis of the program and its implications for the DD population, hopefully, will help to correct this situation. After briefly reviewing the main features of the program, he spells out the specific ways Medicaid can benefit the developmentally disabled. Major attention is given by the author to outlining the provisions of a 1971 amendment to the Social Security Act (P.L. 92-233) which authorized intermediate care payments on behalf of residents in public institutions for the mentally retarded. In addition to describing the specifics of the law, he reviews the progress of HEW's Medical Services Administration in implementing this new statutory provision. Humphrey closes with a series of questions concerning Medicaid which should be considered by state DDSA planners.

The feasibility of closer collaboration between mental health and developmental disabilities is explored in a paper by Nathan Sloate. He suggests that to be workable any such collaboration must rest on a solid foundation of mutual concerns and adequate funding.

Jerry Turem helps the reader to grasp some of the complexities of the present welfare-social service system. He outlines in general terms the historical background and current eligibility criteria for public assistance and social services under two federal-state grant programs—Aid to Families with Dependent Children (AFDC) and Aid to the Permanently and Totally Disabled (APTD). He also discusses the probable impact of major legislative changes incorporated in the State and Local Fiscal Assistance Act of 1972 (P.L. 92-512) and the Social Security Amendments of 1972 (P.L. 92-603) on the developmentally disabled.

Ellen A. Fifer offers the reader an overview of the major provisions of the Comprehensive Health Planning Act and discusses some of the concerns comprehensive health planning agencies share with DDSA agencies. She also suggests a few ways in which comprehensive health formula grant funds might be used to reinforce the goals of state DDSA advisory councils and proposes possible areas for joint action. She ends by reviewing some of the steps which have been taken in the State of Minnesota to create strong working ties between the state DDSA council and the comprehensive health planning agency.

Frederick J. Weintraub reviews developments which led Congress in 1968 to require that at least 10 percent of a state's basic allotment under the Vocational Education program must be used to educate handicapped children. He then traces a rather bleak picture of the Office of Education's response to this mandate over the ensuing four years. A series of brief synopses of exemplary vocational education programs for the developmentally disabled are included in the paper. Weintraub concludes by suggesting a number of ways in which state DDSA council members and staff might move to make more effective use of vocational education funds to benefit DD clients.

The available sources for funding the construction and renovation of facilities for the developmental disabilities through the Department of Housing and Urban Development are reviewed in a paper by Mercer Jackson. In addition to outlining the general eligibility requirements under a variety of HUD financed programs, he specifies the conditions under which handicapped persons may participate. Jackson concludes with a review of some of the steps HUD has taken to make federally subsidized housing more responsive to the needs of the mentally and physically handicapped.

The background and various functional responsibilities of the Bureau for Education of the Handicapped are covered in a paper by Thomas Irvin. He traces the history and growth of the Bureau and outlines its current goals and objectives. He also describes the strategies employed by BEH and suggests a number of issues raised by the Developmental Disabilities legislation from the perspective of the Bureau.

In addition to the papers presented here, one other valuable resource to grow out of the National Conference was an analysis of federal-state plans affecting the developmentally disabled. Entitled *A Guide to Federal/State Plan Review Under the Provisions of the Developmental Disabilities Services and Construction Act,* this volume was prepared by the staff of the Massachusetts Bureau of Developmental Disabilities. Readers who are interested in learning more about the statutory and regulatory requirements for the nine federal-state grant programs specified in Section 134 of the Act will find this publication to be an invaluable tool. Copies may be obtained by writing the Developmental Disabilities Technical Assistance System, 625 West Cameron Avenue, Chapel Hill, North Carolina 27514.

Services Available to the Developmentally Disabled Through the Vocational Rehabilitation State Plan

Emily Lamborn

State vocational rehabilitation agencies can and do provide services to the developmentally disabled including those who are severely handicapped. The kinds of services provided to a particular individual vary in accordance with the needs of that individual, but the range of services which can be provided is very broad, and the services may be provided directly by agency staff or purchased or arranged for through other public or private agencies.

Before discussing further the services available to the developmentally disabled through the Vocational Rehabilitation State Plans, I think it would be well to clear up some common misconceptions about the vocational rehabilitation program.

First, the term "vocational rehabilitation services" is often narrowly construed outside the vocational rehabilitation field. The term, however, is not limited by the Federal Act or Regulations or by State Plans to services which are themselves vocational in nature such as vocational training or placement. On the contrary, services to individuals cover a wide spectrum and include those that are medical or medically related, some which could be described in general as social services, the whole range of education and training, and miscellaneous specified services, including "any other goods or services necessary to render a handicapped individual employable."[1]

Ever since the first Federal vocational rehabilitation law was enacted in 1920, the objective of the Vocational Rehabilitation Act has been to fit disabled individuals for employment. Consequently, a vocational objective for an individual has been a must.

The vocational focus means that services are not provided to those for whom a vocational objective is unrealistic such as children who are too young for vocational planning or the aged whose vocational potential is nonexistent. Although the Federal Act and Regulations have never specified age cut-off points and in recent years exclusion on the basis of age alone has been strictly prohibited in Federal regulations, the need to tie into a vocational objective means that the majority of vocational rehabilitation clients are of working age or close to it.

The vocational objective is not limited to competitive employment. Other kinds of gainful occupation are acceptable—for example, homebound employment, employment in sheltered workshops, family employment and housewife or homemaker. In 1970, over three-fourths of those closed or rehabilitated (76.7 percent) were employed in the competitive market and a little less than a fourth (23.3 percent) were employed in sheltered workshops, were self-employed, or worked as homemakers or unpaid family workers.

Physical disability has been recognized as a factor in eligibility since 1920. Mental disability has been included as a factor since 1943. The acceptance of mental retardates was somewhat slow in getting underway for a number of reasons—e.g., the lack of knowledge as to the condition in relation to employability, confusion in the definitions of retardation, the lack of specialized resources for serving the mentally retarded in the community (lack of special education, lack of rehabilitation facilities, lack of occupational training centers, evaluation and adjustment centers, sheltered workshops) and so on.

The impetus in serving the mentally retarded under the vocational rehabilitation program got underway in the mid 1950's. This reflected in part the growing influence of parent groups in developing services for the mentally retarded, the leadership of some very knowledgeable and dedicated individuals and a growing public awareness of the extent of the need and the possibilities for constructive action. Now legislation and administrative action strengthened the efforts to develop services.

The 1954 amendments to the Vocational Rehabilitation Act added new resources in the rehabilitation program—authority and funds to conduct research and demonstrations; to train personnel needed in the provision of rehabilitation services; to establish rehabilitation facilities and grant authorities for projects to extend, improve, and expand services. In addition, the funds available for regular state program operations were increased substantially and most states were able to serve not only more people but to serve them more effectively. All this meant new program emphases could be developed.

The growth in the number of the mentally retarded served can be easily seen if we compare the numbers of mentally retarded rehabilitated in 1950 and in 1970 and their proportion of the total numbers. In 1950, 493 mentally retarded persons were rehabilitated—less than 1 percent of the total of 59,597 persons rehabilitated. In 1970, 30,356 mentally retarded persons were rehabilitated—11.8 percent of the 266,975 persons rehabilitated.

Substantial amounts of money are spent by state vocational rehabilitation agencies to serve the mentally retarded. It is estimated that over $65,000,000 was spent in 1970 under State Vocational Rehabilitation Plans for the rehabilitation of the mentally retarded.[2]

There is not so much progress in rehabilitating people with other kinds of developmental disabilities. For example, although the number of epileptics rehabilitated per year has increased from 1,073 in 1950 to 4,267 in 1970, the percentage of the total has actually dropped slightly—from 1.8 percent to 1.7 percent. There were 1,476 cerebral palsied individuals rehabilitated in 1967;

in 1970 there were 1,754–less than 1 percent of the total.

During the hearings on the 1972 amendments to the Vocational Rehabilitation Act,[3] many witnesses spoke of the need for vocational rehabilitation agencies to serve more of the severely handicapped. Of course, severely handicapped people are served if vocational rehabilitation services may reasonably be expected to render such an individual fit to engage in a gainful occupation.[4] It should be recognized, however, that resources–funds, staff, facilities–are not sufficient to serve more than a fraction of the disabled people who can benefit from rehabilitation services and that these resources must be used to serve people with all kinds of physical or mental disabilities.

HOW STATE VOCATIONAL REHABILITATION AGENCIES SERVE THE DEVELOPMENTALLY DISABLED

There is a state plan for vocational rehabilitation in each of the 50 states, the District of Columbia, Guam, Puerto Rico and the Virgin Islands. The program is state-administered and is statewide in nature.

In not quite half of the states the general vocational rehabilitation program is organizationally affiliated with education or vocational education. In three states it is a division of a department of labor, or labor and industry. In other jurisdictions it is within a department or agency which includes social services or a combination of health programs, social services and related programs; or is an independent commission, department, or agency which is not organizationally affiliated with another state department or agency.

In one half of the states the vocational rehabilitation program for the blind is located in the same parent department or agency as the general vocational rehabilitation program. In the other states, it is in an independent commission or agency or is located in a parent agency different from that of the general program.[5]

State vocational rehabilitation agencies have a network of offices and facilities in which services are provided to the disabled. Almost all general vocational rehabilitation programs and most agencies for the blind have district, local, or branch offices and some have regional or area offices as well. In addition, many states operate one or more rehabilitation facilities and almost all state vocational rehabilitation agencies are engaged in cooperative programs of service with other public agencies which involve additional places where vocational rehabilitation agency personnel are stationed in order to bring services to disabled people. The following table summarizes the number of offices, rehabilitation facilities and cooperative programs operated by state vocational rehabilitation programs in 1970.[6]

	Offices	Rehabilitation Facilities	Cooperative Programs	Total
General Agencies	1,616	242	1,440	3,2[illegible]
Agencies for the Blind	186	35	49	2[illegible]
Total	1,802	277	1,489	3,568

State vocational rehabilitation agencies also utilize existing community resources—public and private—in the provision of rehabilitation services. These include schools, hospitals, clinics, social service agencies, and specialized facilities and programs, including all types of rehabilitation facilities. Ordinarily, State vocational rehabilitation agencies purchase services from these institutions or agencies unless some other arrangement is more suitable.

State vocational rehabilitation agencies also purchase services from individual practitioners such as doctors, medical specialists, psychologists, nurses, therapists and from such vendors as prosthetic or orthotic or hearing aid dealers or businesses which can provide needed occupational tools, equipment and supplies.

The services to be provided are specified in the rehabilitation plan developed for each eligible client based upon data secured in a diagnostic study and, if provided, an extended evaluation.[7]

The diagnostic study consists of a comprehensive evaluation of pertinent medical, psychological, vocational, cultural, social, and environmental factors in the case. The study must be adequate to provide the basis for: (1) establishing that a physical or mental disability is present; (2) appraising the current general health status of the individual; (3) determining how and to what extent the disabling conditions may be expected to be removed, corrected, or minimized by physical restoration services; and (4) selecting an employment objective commensurate with the individual's interest, capacities and limitations. The study must also include, in all cases to the degree needed, an evaluation of the individual's personality, intelligence level, educational achievements, work experience, vocational aptitudes and interests, personal and social adjustment, employment opportunities, and other pertinent data helpful in determining the nature and scope of services to be provided for accomplishing the individual's vocational rehabilitation objective.

The diagnostic study and evaluation and the development of an individual plan for vocational rehabilitation services are key features of the rehabilitation process. They are used regardless of where the client is served: by the state vocational rehabilitation agency—in a local office, in a state-operated rehabilitation facility, or in a cooperative program of service. They are used whether the services are provided directly by the state vocational rehabilitation agency, by purchase, or cooperative arrangement of some sort.

The cooperative programs of service have become, in most states, a major service-delivery system and are particularly pertinent for services to the developmentally disabled. "Cooperative programs of service" means just that. (It does not mean referral for service arrangements which exist between agencies in all states).

Cooperative programs of service are programs in which rehabilitation services are provided in combination with services such as educational, health or social services.

The agencies providing the services do so on an interlocking basis or a service continuum. Ordinarily, each invests staff and funds in a program of services directed to serve more effectively a target population.

Among the first cooperative programs of services were those in which vocational rehabilitation agencies pooled resources with public school systems in order to meet the needs of young, disabled people. All of these programs cover students of high school age and many cover students in junior high.

A study of these programs made in 1969 disclosed that all of these programs served the mentally retarded. In fact, the mentally retarded represented almost 60 percent of the total caseload of the cooperative public school programs. Other types of disabilities served in some states include the mentally ill, speech and hearing, blind and other visual, and other physical handicaps. The total number of young people served by state vocational rehabilitation agencies in these cooperative school programs in fiscal 1969 in the 37 states reporting was close to 100,000.[8]

Another type of cooperative program of service which is well established in some states is the kind located in a state institution such as a state mental hospital or a state school for the retarded. This type of cooperative program results in deinstitutionalization for many of those served. An organized study of the character and effects of these institutionally based cooperative programs is greatly needed.

Another frequent characteristic of cooperative programs of service is the development and utilization of rehabilitation facilities. For example, almost all state vocational rehabilitation agencies make use of rehabilitation facilities in providing services under the cooperative school programs. The facilities are used most often to provide evaluation and adjustment services as well as skill training.

The cooperative programs with state institutions often adapt the rehabilitation facility model in one of its forms. Cooperative programs within the community also make use of the rehabilitation facility model or are tied into an existing facility.

So far we have dealt on service programs as such. There are, however, other ways the developmentally disabled are assisted under state vocational rehabilitation plans. A few are described below.

Construction and Establishment of Rehabilitation Facilities

In all but a few states, state vocational rehabilitation agencies have used vocational rehabilitation grants to pay for the alteration or expansion of existing buildings or the construction of new ones for use as rehabilitation facilities and for their equipment and initial staffing (over $51,000,000 in fiscal 1970 alone).[9] In addition, they sponsor rehabilitation facility grants from other sources. Some of these facilities specialize in serving people with a particular type of disability such as mental retardation. Others serve people with a wide range of disabilities.

Planning

State vocational rehabilitation plans provide for continuing statewide studies of the needs of handicapped individuals and how these may be most effectively met. Planning studies for rehabilitation services are required to be coordinated, to the maximum extent possible, with related planning activities. It is obvious that planning for those with developmental disabilities should be coordinated with planning for vocational rehabilitation services. One of the areas in which planning together could be most constructive is in the linkage of institutional and community programs serving the developmentally disabled.

Research and Training

The vocational rehabilitation program has authority and funding for research and training. This can and has been used for research in the rehabilitation of those with developmental disabilities and for training personnel to work with them. There are three research and training centers focusing on mental retardation and funded under the Vocational Rehabilitation Act. There is also a host of individual projects.

It would be very helpful in the development of research strategy to consider the systematic study of ongoing cooperative programs serving those with developmental disabilities. As noted above, a study of the character and effort of institutionally-based cooperative programs is greatly needed. Probably of equal importance would be the study of cooperative programs of service in the community. The development of new patterns of services and the replication of sound innovations as demonstrations (as was done some years ago with occupational training centers) should also be considered.

State vocational rehabilitation programs are flexible and willing to innovate. They are also most willing to join with other programs to meet the needs of disabled people. The field of developmental disabilities could indeed capitalize on this willingness and on the experience state vocational rehabilitation programs have had in cooperative programs of service in order to enrich and increase services to those with developmental disabilities.

THE REHABILITATION PROGRAM OF THE FUTURE

As noted above, the 1972 amendments to the Vocational Rehabilitation Act were vetoed by the President. The bill, however, was passed by the Senate and the House without a dissenting vote and has been reintroduced in the 93rd Congress.[10] It is expected that it will be enacted early in the session. Consequently, it is important to note its major thrusts.

One of the most significant aspects of the bill is its emphasis on serving the severely handicapped. For example, although Title I[11] retains the focus on the achievement of a vocational goal, the order of selection gives priority to those with the most severe handicaps. Furthermore, Title II provides supplemental grants to assist states in meeting the needs of handicapped individuals for whom a vocational goal is not possible or feasible. The emphasis on the severely handicapped is also reflected in the research provisions, including special authority for rehabilitation engineering research centers, centers for spinal cord injuries, services for end-stage renal disease and rehabilitation services for older blind individuals.

Another important feature of the rehabilitation program of the future will be greater recognition of the consumer voice. In the past, regulations required that at least one-third of the membership of advisory committees for statewide planning be disabled persons. Both the extended evaluation plan for a disabled individual and the vocational rehabilitation plan were required by regulations to be formulated with the client's participation.

Under the pending legislation, the requirement for client participation in an individualized written rehabilitation program is required by law and strengthened. The state plan itself must provide satisfactory assurances that the state agency will take the views of recipients[12] into account in connection with matters of general policy arising in the administration of the state plan. Provision is also made for obtaining the views of those served in the Secretary's evaluation of programs and projects.

There is provision for membership of the handicapped on the National Advisory Council and State Advisory Councils and the National Commission on Transportation and Housing for Handicapped Individuals.

There are various other provisions designed to ensure that careful consideration is given to the needs of handicapped individuals as they see them and to facilitate their access to and receipt of services. Among those provisions are those for client assistance projects and those delineating functions of the Office for the Handicapped; e.g., providing a clearinghouse for information and resource availability for handicapped individuals.

In addition to the introduction of the concept of comprehensive rehabilitation services to those with a nonvocational objective (although envisaged as a supplemental, not a predominant part of the program) in pending vocational rehabilitation legislation, there are provisions in the Social Security Amendments of 1972[13] which will greatly affect both the nonvocational and the vocational aspects of the vocational rehabilitation program.

Without attempting to increase all of these provisions, mention will be made of some of the most far-reaching:

- increase in the amount of social security trust fund monies that may be used to pay the cost of rehabilitating social security disability beneficiaries;
- extension of medicare to social security disability beneficiaries after 24 months of entitlement to disability benefits;
- imposition of a penalty for failure to provide child health screening under medicaid;
- supplemental security income for the aged, blind, and disabled, using uniform standards with respect to income and resources and with respect to blindness or disability;[14]
- referral of a blind or disabled individual under 65 who is receiving benefits to the appropriate State vocational rehabilitation agency for a review of his need for and utilization of rehabilitation services;[15] and
- provision of services to the aged, blind, or disabled to help them attain or retain capability for self-support or self-care.[16]

The rehabilitation program of the future will be greatly influenced by the emphases in pending vocational rehabilitation legislation and by the provisions of the Social Security Amendments of 1972. It is imperative that those interested in the developmentally disabled plan with the vocational rehabilitation program to develop the fullest potential for serving these handicapped people.

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[1] In fact, almost the only services which could not be classified as vocational rehabilitation services are those related to employment costs, e.g., wages or an employer subsidy. Expenditures for such purposes in either competitive or sheltered employment (except those related to training) are limited to special programs such as "new careers" or "projects with industry."

[2] This amount does not include what was spent under the Vocational Rehabilitation Act in 1970 for research and other projects for the benefit of the mentally retarded.

[3] Vetoed by the President on October 27, 1972. Its provisions for the severely handicapped are discussed later as part of the rehabilitation program of the future.

[4] This factor in eligibility is often referred to as "feasibility." The expectation is affected both by the needs of the individual and the availability of the facilities and services he needs.

[5] The Vocational Rehabilitation Act provides for a sole state agency except where there is a separate state agency for the blind authorized to provide them such vocational rehabilitation services. Depending upon state law, such a separate agency may serve a person who both is blind and has a developmental disability.

[6] *State Agency Exchange,* February 1971.

[7] An extended evaluation period is used to determine the rehabilitation potential of an individual when there is inability to determine that there is a reasonable expectation that vocational rehabilitation services may render the individual fit to engage in a gainful occupation—a criteria for eligibility for vocational rehabilitation habilitation services. (Other criteria are the presence of a physical or mental disability and of a substantial handicap to employment.)

[8] *State Agency Exchange,* December, 1969.

[9] In addition, as previously noted, state vocational rehabilitation agencies purchase services from existing facilities (over $77,000,000 worth in fiscal 1970).

[10] S. 7 and H.R. 17. Additional identical bills have been introduced in the House.

[11] Grants to States for basic vocational rehabilitation services and innovation and expansion grants.

[12] Or, in appropriate cases, their parents or guardians.

[13] P.L. 92-603.

[14] An infant or child who meets the definition of disability or blindness and the tests of income and resources will be paid benefits.

[15] The Secretary of HEW is authorized to pay the state vocational rehabilitation agency costs incurred in the provision of rehabilitation services to individuals so referred.

[16] Subject to Section 1130 of the Social Security Act.

Services Available to the Developmentally Disabled Through the State Maternal And Child Health Plan

Rudolf P. Hormuth

STATE CRIPPLED CHILDREN'S SERVICES

Section 501, Title V, Social Security Act, authorizes annual formula grants to the States to find children who are crippled or who are suffering from conditions leading to crippling and provide them with medical, surgical, corrective and other services.

1972 fiscal year appropriation	$62,272,000
1971 fiscal year appropriation	58,600,000

The Crippled Children's programs locate children with crippling conditions and see that they are diagnosed and receive the medical and other health-related care, hospitalization, and continuing follow-up that they need. Free diagnostic services are available to every child brought to the clinics. The CC agencies help parents with financial planning for treatment and care, and may assume part or all of the cost of care, depending on the child's condition, the family's resources, and availability of funds.

Each of the CC agencies operates under a State law which either defines crippling conditions that will be covered or directs the agency to define them. All the States include children under 21 with handicaps requiring orthopedic or plastic treatment, such as cleft palate, club feet, and chronic conditions affecting muscles, bones and joints. Nearly all States include rheumatic and congenital heart disease, epilepsy, cystic fibrosis, and certain vision and hearing disorders. The States have broadened their programs over the years to include many kinds of handicapping conditions and long-term illnesses. Thus for example, over 45,000 children with diagnosis of various forms of mental retardation received medical services in the crippled children's program during the past year.

A total of 497,959 children, or slightly more than 6 out of every 1,000 children in the population, received physicians' services under State crippled children's programs in 1971. Hospital inpatient care was provided to 82,000 children.

In 1971, children between 5 - 9 years of age comprised the largest users of the program (29.7 percent), with the next largest groups those between 1 - 4 years (26.3 percent) and 10 - 14 years (22.9 percent). The number of children between 15 and 17 using the program was 10.3 percent of the total, and 4.1 percent were under one year of age.

Expenditures

About $154 million was spent by the States for services to crippled children in fiscal year 1970. About 38 percent of the total spent was from Federal sources, the balance from State and local sources. The total amounted to $1.84 per child under age 21 in the population. In a number of states the reported amount of state and local expenditures was more than double the Federal expenditure.

CC Services of Special Interest to State Planning and Advisory Councils.

The 1963 Social security amendments provided for increased Federal funds for the Crippled Children's program and for the earmarking of some of these funds specifically for services for mentally retarded children. From 1963 through 1970, $40.5 million of Federal CC funds earmarked for this purpose have been utilized.

These funds have been used by some States to provide corrective care for institutionalized retarded children, or as special projects grants in selected medical centers to develop special clinics for multiply handicapped children. These programs are demonstrating the kind of staff and services required to meet the total needs of such children through a single comprehensive clinical setting and program.

An additional use which has been made of these Crippled Children's funds earmarked for mental retardation is for special project grants for cytogenetic and biochemical laboratory services and genetic counseling programs. Such programs are usually extensions of special clinical services for handicapped children located at hospitals or medical centers. The services include chromosome analysis and diagnosis of various conditions which may be given to parents seeking advice on genetic questions. These laboratories also provide continued monitoring of patients in the State with metabolic diseases, and train the necessary professional personnel to deliver these services.

During fiscal year 1972, 21 special laboratory programs of this type were in operation. They provided chromosome studies on approximately 4,500 patients and their families with a known or suspected genetic problem, and processed some 90,000 biological specimens to check for a variety of conditions. Of the patients served some 70 percent were under 1 year of age, 9 percent were from 1 to 4 years, 5 percent from 5 to 9, and 16 percent over 9 years of age. Approximately 18 to 20 percent of these families came from low-income minority groups.

Genetic counseling was provided, based on these cytogenetic and biochemical laboratory findings and comprehensive clinical evaluations.

STATE MATERNAL AND CHILD HEALTH SERVICES

Section 501, Title V, Social Security Act, authorizes annual formula grants to the States to extend and improve health services for mothers and children, especially in rural areas.

1972 fiscal year appropriation	$59,250,000
1971 fiscal year appropriation	59,250,000

Programs to promote good health for mothers and children are basically programs to prevent ill health and infectious disease, to safeguard the period around pregnancy, and to minimize health hazards by identifying them as early as possible. State maternal and child health service programs reported these services for fiscal year 1970:

For mothers: Maternity clinics, nursing services, hospital inpatient care, family planning services, dental care for expectant mothers, and classes for expectant parents. Some 332,000 women received maternity clinic services, 529,000 received maternity nursing service, and 36,000 hospital inpatient care in fiscal 1970. In addition, over .5 million women received family planning services.

For children: Well-child clinics for health supervision of babies and children, nursing services, pediatric clinics, hospital inpatient care (mostly of premature infants), school health examinations and screening tests, immunizations, and mental retardation clinics. The well-child clinics served 1,474,000 children in 1970; 2,391,000 children received nursing service; nearly 9 million were screened for vision problems; 736,000 received dental treatment; about 60,000 infants and children received inpatient hospital care. Vaccinations against rubella were given to 3,784,000 children.

Expenditures. States and other jurisdictions reported expenditures of $165,094,082 for maternal and child health in fiscal year 1970. State and local funds made up about 70 percent of the total. The total amount spent represents $2.05 per individual under age 21 in the total population.

MCH Services of Special Interest to State Planning and Advisory Councils.

Between 1956 and 1970 a total of $68.7 million of Federal MCH funds had been earmarked by the Appropriations Committee to demonstrate the unique and specific contributions which can be made on a State and local level in evolving balanced services for retarded and handicapped children who show a developmental lag.

These funds have been used for special project grants to demonstrate new and better ways of meeting needs and delivering care to these children and their families in two major areas:

1. Special Clinical Services. Support of clinical services for mentally retarded children is one of the most important uses for MCHS mental retardation funds. The services provided include diagnosis, evaluation of a child's capacity for growth, the development of a treatment and management plan, interpretation of these findings to parents, and follow-up care and supervision. Mental retardation clinic services were given to 57,000 children in 150 clinics supported by MCHS funds during the fiscal year 1971. These clinics operated in all but three States.

Children are being seen at these special clinics at an earlier age than before, through multiple screening procedures offered by the State maternal and child health programs. In 1970, 30.6 percent of the children seen in clinical programs were 5 years of age or under and 76 percent were under 10 years of age.

New patients numbered 24,300 with the median age 6.7 years. The condition most frequently associated with diagnosis of retardation in the new patients, was "uncertain cause with functional reaction manifest," accounting for 32 percent of the new patients. Prenatal influences were cited as the principal cause of retardation for 25 percent of the children. The other leading diagnostic listings were "unknown cause with structural reactions manifest," 18 percent of the children, and trauma 12 percent of the children.

*2. **Prevention.*** A major emphasis in the prevention of mental retardation within the past few years has been in relation to phenylketonuria (PKU). This inborn error of metabolism has in the past been responsible for 1 percent of the population in our State institutions for the mentally retarded. By detecting families with the condition and by placing young infants with the condition on a special diet, mental retardation can usually be prevented. MCHS has been working with State health departments in developing and trying out various screening and detection programs, developing the necessary laboratory facilities, and assisting States in providing the special diet and follow-up programs for these families.

Although such programs may be initiated without a legislative requirement, in many States laws have been enacted on this subject. By July 1970, 43 States had such laws, most of them making screening for PKU mandatory. The 43 States are:

Alabama
Alaska
Arkansas
California
Colorado
Connecticut
Florida
Georgia
Hawaii
Idaho
Illinois
Indiana
Iowa
Kansas
Kentucky
Louisiana
Maine
Maryland
Massachusetts
Michigan
Minnesota
Missouri
Montana
Nebraska
New Hampshire
New Jersey
New Mexico
New York
North Dakota
Ohio
Oklahoma
Nevada
Oregon
Pennsylvania
Rhode Island
South Carolina
Tennessee
Texas
Utah
Virginia
Washington
West Virginia
Wisconsin

During the past year approximately 90 percent of the total registered live births in the 50 States and the District of Columbia were screened. This screening effort by the States, supported through MCHS, turns up approximately one confirmed case for every 16,000 live registered births. Annually about 225 infants born to families in which no previously known sibling with PKU had been delivered are being detected, subsequently confirmed as having

PKU, and treated.

Interest continues to increase in metabolic diseases other than PKU that led to mental retardation. MCHS is continuing to support a study of the clinical application of screening tests to detect galactosemia, maple syrup urine disease, and histidinemia. Also, support is being given to studies of new approaches to broader screening methods which would make available a battery of automated tests for detecting metabolic diseases. The effectiveness of this "seed money" can be shown by the fact that, of several hundred projects initiated, less than six have been terminated or discontinued; that the States have invested about the same amount as the project grant to extend and expand the projects; and that project staffs have provided primary leadership in statewide planning efforts on behalf of the retarded and have been intensively involved in the development of the University-Affiliated Center program as well as in coordination of services.

GRANTS FOR HEALTH CARE PROJECTS

Since 1963 several new maternal and child health services programs have been established under title V of the Social Security Act. These have been developed in response to serious shortages of health services for low-income families in the central cities and in isolated rural areas. In the areas they serve, these programs provide continuous high-quality health care for mothers and children, many of whom previously experienced health care only in emergencies.

Maternity and Infant Care Projects

Section 508, title V, Social Security Act, authorizes grants for projects to help reduce the incidence of mental retardation and other handicapping conditions caused by complications associated with child-bearing and to help reduce infant and maternal mortality by providing necessary health care to high-risk mothers and their infants.

1972 fiscal year appropriation	$42,675,000
1971 fiscal year appropriation	38,565,000

Fifty-six Maternity and Infant Care Projects were in operation at the end of fiscal year 1972, located in 35 States, the District of Columbia and Puerto Rico. While more than 60 percent of the Maternity and Infant Care Projects serve cities of 100,000 or more, projects are also located in rural and urban-rural populations in such States as Alabama, Georgia, Florida, Arkansas, Idaho and others. All the projects serve localities which in the past showed much higher infant and maternal mortality rates than the nation as a whole.

According to provisional data, a total of 141,000 new maternity patients were admitted to the M & I projects during fiscal year 1972. New family planning admissions in fiscal year 1972 totaled 130,000, and infants admitted totaled approximately 45,000.

About 60 percent of all women admitted for maternity care in the projects were black. Of total new maternity admissions, 1.9 percent were less than 15 years old, 3.6 percent were 15 years old, 89.6 percent were between 16-34 years and 4.9 were 35 years and over.

Projects for Intensive Care of Infants

Section 508, title V, Social Security Act, authorizes grants for projects to provide necessary health care to infants during their first year of life when they have conditions or are in circumstances which increase the hazards to their health, in order to help reduce the incidence of mental retardation and other handicapping conditions caused by complications associated with childbearing and to help reduce infant mortality.

1972 fiscal year appropriation	$753,000
1971 fiscal year appropriation	450,000

The Maternal and Child Health Service (then a part of the Children's Bureau) began supporting programs for premature infants, now often termed low-birth-weight infants, in the 1940's. The central focus of these units then was on expert nursing care. The 1960's have seen a transition from premature nurseries to intensive care units for high-risk newborn infants. Though most of the infants in intensive care are low-birth-weight babies, intensive care units also admit other infants who need special monitoring and care. Increased medical, nursing, and laboratory support, as well as more sophisticated equipment, is required for the very specialized care emphasized in intensive care units for newborns.

Since the long-range goal of such programs is the prevention of morbidity and mortality in infants, an effective program must begin long before the birth of the baby, with improved care of the mother through comprehensive prenatal and interconceptional care.

By the end of fiscal year 1972 the Maternal and Child Health Service was supporting eight intensive care units which were serving infants not only from the sponsoring hospital but also from hospitals in a given city, a county, statewide or in several States.

Projects for Comprehensive Health Care of Preschool and School-Age Children

Section 509, title V, Social Security Act, authorizes grants for comprehensive health care programs to meet the medical, dental, physical and emotional health needs of children and youth, particularly in areas with concentrations of low-income families.

1972 fiscal year appropriation	$47,400,000
1971 fiscal year appropriation	43,835,000

Fifty-nine Children and Youth projects were in operation at the end of fiscal year 1972, serving an estimated 456,000 children. They were located in 23 States, the District of Columbia, the Virgin Islands and Puerto Rico. Sixty-seven percent of the projects were located in central city areas, 23 percent in peripheral urban or rural areas, and 9 percent in more than one location.

The geographic areas covered by the projects range from 0.11 to 6,373 square miles, and the number of registrants from 780 to 45,000. Some projects have recently narrowed their geographic focus to provide more effective service.

Of the 24 projects which have done so, 10 are operated by medical schools, nine by health departments and five by hospitals. Hospital projects serve the lowest median area (2 square miles) compared with 10 square miles for medical school and 19.5 square miles for health department projects.

A breakdown by race shows that 64 percent of registrants are black, 32 percent are white, 4 percent of other races. Of total registrants, 12.5 percent are Spanish-speaking. Girls outnumber boys in each of the racial and ethnic categories. Median age for registration was about 5 years. The age group from 5 to 9 has the highest percentage of registered children, followed by the 1 to 4 group. Most projects focus their efforts on children between the ages of 0-14.

A relatively high percentage of children in the 5-9 group receive initial DPT and DT shots, indicating a low immunization base in the geographic areas served by the C & Y program. Of all specific items of service, immunizations are provided most frequently.

At least one of each four new registrants has an acute medical episode of care before initial health assessment. The number of registrants with acute episodes of care decreases dramatically after comprehensive health care services have been provided. While correctable episodic diagnostic conditions show a dramatic decline after initial health assessment, provision of comprehensive health service does not seem to affect the incidence of episodic diagnostic conditions such as infections, allergies and injuries. Environmental factors may override the primary prevention efforts to reduce the frequency of these conditions.

Nevertheless, a recent report on diagnostic conditions found at recall assessment stated that the frequency of "well child by medical examination" increased by at least 50 percent; preventable conditions decreased and correctable conditions were reduced.

The average annual cost per child in the C & Y projects was $201.26 for 1968, $162.47 for 1969, $149.82 for 1970, and $127.00 for 1972.

Dental Health Projects

Section 510, title V, Social Security Act, authorizes grants for projects that promote the dental health of children and youth of school and preschool age, particularly in areas with concentrations of low-income families.

1972 fiscal year appropriation	$1,180,000
1971 fiscal year appropriation	500,000

Dental care has been available through the State maternal and child health and crippled children's programs and the Children and Youth and Maternity and Infant Care Projects. In 1971, for the first time, a program of special project grants was launched to promote the dental health of children through comprehensive dental care projects. This program was authorized by the Child Health Act of 1967, and permits provision of dental care through a variety of approaches which emphasizes prevention and continuing dental supervision. Through fiscal year 1972, seven projects in this area have been funded.

TRAINING

Under Section 511, title V, Social Security Act, personnel are trained for health care and related services for mothers and children, particularly mentally retarded children and children with multiple handicaps. Training grants are made to public and nonprofit private institutions of higher learning. The bulk of these funds are being used to support staff and trainees in the University-Affiliated Center program.

Training activities are also supported by funds authorized under sections 503 and 504 of title V for projects which may contribute to the advancement of maternal and child health and crippled children's services.

1972 fiscal year appropriation	$15,071,000
1971 fiscal year appropriation	11,200,000

University-Affiliated Centers

The program designed to provide comprehensive multidisciplinary training of specialists who will work with the handicapped and retarded is based on a concept of multi-agency funding and multi-departmental university participation. It had its beginning in 1963 under P.L. 88-164, which authorized Federal support in the construction of facilities to house such training efforts. At many of the universities that applied, MCHS was already involved in the funding of clinical services.

In 1965 this role was expanded to include support for faculty and students in the health services component of the training programs, which has now reached approximately 65 percent of its projected development through the support from MCHS of 20 programs. The planned and projected development of educational, rehabilitation, research and other components of the program has been somewhat slower than anticipated.

The major impact of these programs during 1972 has continued to be in raising levels of teaching and service and influencing a variety of basic curriculum changes in the affiliated degree-granting departments, colleges, and universities. This is brought about by interrelationships between the colleges and universities and the centers. For example, the colleges are using the centers to train their students, and give degree recognition for the training the centers provide. There is a system of dual appointments–the core faculty holds staff appointments in the university department or school as well as at the center. Each health service component maintains an average of 17 such relationships through formal agreements.

Comprehensive services to children and families provide the clinical basis for the multidisciplinary training in these programs. In 1972 the 20 programs evaluated over 16,000 children and their families to select the appropriate teaching situations for students enrolled in the program. All of these children and their families received some type of service, either as a model of exemplary care by the faculty and staff or by referral to an existing service program. Over 900 health services positions, representing approximately 725 man-years, were budgeted by these programs to provide this patient service and to carry out the teaching responsibilities.

Although many children and their families do benefit from the exemplary services provided by staff and trainees at the denters, the major responsibility for meeting their health, education and social needs remains with the community. The programs have developed extensive collaborative relationships with a large number of community agencies to meet these needs and to assist in the upgrading of staff skills in the agencies.

The long-term trainees on MCHS stipends in University-Affiliated Centers during fiscal year 1972 included:

Psychologists	65
Pediatricians & Obstetricians	51
Medical Social Workers	86
Speech pathologists & Audiologists	47
Pedologists	20
Nurses	8
Occupational Therapists	9
Physical Therapists	10
Psychiatrists	6
Nutritionists	9
Geneticists	3
Administrators	6
Dental Auxiliaries	6

RESEARCH GRANTS

The MCHS research grants program is concerned with improving the functioning and effectiveness of maternal and child health and crippled children's services. Special emphasis is given to projects which will help in studying the need for, the feasibility, costs and effectiveness of comprehensive health care programs in which maximum use is made of health personnel with varying levels of training.

Currently 96 research projects are being supported. Some examples of recent projects are: evaluation studies of health care projects; study of the use of allied health workers in maternity care; survey of group care facilities for children; study of the relation between maternal nutrition and the course of pregnancy.

Grants for research projects may be made to nonprofit institutions of higher learning and to public or other nonprofit agencies and organizations engaged in research in maternal and child health or crippled children's programs. For 1971 the appropriation for this program was $5,735,000.

INTERNATIONAL ACTIVITIES

Research and training are sponsored abroad by MCHS using foreign currencies available under the PL-480 program. Research areas are selected which are of mutual interest to the U.S. and the cooperating country and which will complement work going on in the U.S. Also using PL-480 funds, support is being given for study abroad by U.S. scientists in the field of maternal and child health.

Other MCHS international activities include planning programs for foreign visitors who are in the U.S. for training in maternal and child health, technical assistance to the nutrition program of AID, and an active role in U.S. participation in UNICEF.

ADDENDUM

The discussions which took place in the two workshops on Services Available to the Developmentally Disabled through the State Maternal and Child Health Plan initially focused on clarifying existing and current services being provided through the MCHS program. There was some exploration of possible restrictive impediments in the States' legal and administrative definitions; adequacy of the delivery of these services; questions about possible narrowness in the scope of some State services as well as the effectiveness of some services (particularly in the area of early case finding).

Workshop Assessment of Available Services through the State MCH Plan

The consensus of both workshop groups in this area appeared to be:

1. The State MCH and CC programs in general are well established and are providing the kind of basic services for developmentally disabled children that the State Planning and Advisory Councils are charged with promoting and coordinating.

2. While the Federal legislative authority for MCHS programs is quite broad, program development in the States has been restricted by a decreasingly proportionate allocation of Federal, State and local resources for children and a lack of any increase in resource allocation for basic services to the developmentally disabled over 21 years of age.

3. Many of the models of service delivery demonstrated by MCHS programs are most effective and efficient (particularly those models incorporating concepts of multidisciplinary comprehensive approaches including follow-up care, etc.). New models do not need to be developed in most instances. Rather, the existing ones need to be implemented and strengthened.

4. While greater efficiency in the delivery of some of these needed services to the developmentally disabled could be achieved through the efforts of the State Planning and Advisory Councils, current available resources could not achieve delivery of these services to most of the large numbers of developmentally disabled individuals of which we are now aware.

Communication and Coordination between State Councils and MCHS Programs

The bulk of the workshop participants were members of their respective State Councils as well as State or local MCHS program representatives. From their point of view there is adequate and appropriate input from the MCHS services into the State planning effort. There was considerable evidence presented by workshop participants of attempts by State Councils to fill in gaps in existing MCHS services. Two examples of problem areas were mentioned by the groups:

1. One State Council determined priorities for filling gaps in services by: (1) eliminating those areas in which some legal or legislative authority for delivery of a needed service had been assigned to a Federal or State agency, and

(2) setting up the remaining needs in order of priority with those services having the lowest total authorization of funds at the top of the list. The group pointed out that assigned legislative responsibility to provide a service does not always imply implementation, and that levels of authorization seldom equal actual appropriations. It was felt this approach to setting priorities was not only unrealistic, but tended to penalize established services, such as MCHS, in which needs do exist.

2. There was concern about participation by the State Planning and Advisory Councils in the development of service delivery plans ordered by the courts in response to current class action suits on behalf of handicapped groups denied services or specific rights to services. Only one State Council represented in the two workshops had become involved in developing such a court-ordered plan. The MCHS program representatives expressed concern that without the State Advisory Council input in such plans on behalf of the total State service system, including MCHS, there could be a serious disruption of a number of services in efforts to meet the court-ordered action.

New Strategies and Approaches to Service Delivery

The bulk of discussion time in both workshops was devoted to attempts to clarify and interpret the impact the "new strategies" for the delivery of services to the developmentally disabled might have on the total program. Included in these considerations were discussions relating to decentralization, grant consolidation, service integration, etc. The following areas evolved as specific concerns of the participants and as areas requiring the attention of the State Advisory Councils:

1. Title XIX of the Social Security Act – its use in achieving a higher quality of care and follow-up service.

2. Revenue Sharing of Health Dollars – needed clarification for the Councils as to which program funds will be included in this and which health services the States are expected to operate with such funds.

3. Expiration of Project Grant Authority under Section 508, 509 and 510 of the Social Security Act. For fiscal 1974 special project grants for Maternal and Infant Care, Intensive Infant Care, Family Planning, Children & Youth and Dental Care for Children will terminate, and funds for such programs will be included in formula allocations to the States. While each State MCH plan must contain at least one acceptable project in each of these five categories, this will mean a decrease of total Federal funds for some of the larger urban States in which a number of M & I or C & Y projects were operating in the cities. Some of the smaller States which did not have a number of such projects in operation will on the other hand receive some increases. What happens to these programs and how some of the larger urban program might be maintained with decreased fund allocations to the States are areas of concern for the State Advisory Councils.

4. National Health Insurance Program. Most participants felt that some type of National Health Insurance Program would be developed in this country. They expressed concern that, as in other countries, the specific needs of the developmentally disabled might not be covered (or coverage might not be

possible or practicable) under an actuarial system. The participants stressed the need for the State Advisory Councils to involve themselves in considerations of such health insurance programs and be prepared to document the needs of the developmentally disabled, and present plans to meet such needs, at the time that a National Health Insurance program is considered.

Services Available to the Developmentally Disabled Through Title XIX of the Social Security Act

Richard L. Humphrey

In order to discuss a program as far reaching and important as Title XIX, it is necessary to provide some background information about Medicaid, as Title XIX is commonly called.

Medicaid is the joint State and Federal program that provides the framework for financing the delivery of health care services to the poor and near poor. To date, 53 States and jurisdictions including all the States except Arizona have adopted a Title XIX program.

In brief, Medicaid established a basic package of required medical services, defined the segment of the population to receive it, stipulated that qualified providers of medical services were to be paid for the services they provided, and authorized tax funds for this purpose. In addition to mandatory requirements, Medicaid also contains a number of optional provisions which States may include in their Title XIX medical assistance program.

For example, under currently applicable legislation, if a State participates in Title XIX, it must provide medical assistance to the so-called categorically needy, those receiving financial assistance under one of the Federally aided public assistance programs for the aged, the blind, the disabled, or families with dependent children. In addition, States may opt to include the medically needy, those who meet requirements for one of these four categories except that their incomes are too high to receive money payments but not enough to pay for medical needs. Among other optional groups, States may cover all children under the age of 21 who meet their income and resource requirements. H.R. 1, signed into law as P.L. 92-603, will make changes in the adult categories, mostly effective January 1, 1974. I shall discuss the provisions of P.L. 92-603 later in this paper.

The basic package of required services which a State must provide for the categorically needy are: inpatient hospital services; outpatient hospital services; laboratory and X-ray services; physician services; skilled nursing home services for persons aged 21 or over; early and periodic screening diagnosis and treatment services for children under 21; home health services for anyone entitled to skilled nursing home services; and family planning services.

In addition, a State may include in its title XIX plan a wide range of additional services and the Federal government will share in the cost of providing them. Those optional services most pertinent to the developmentally disabled include: prescribed drugs, dental services, physical and occupational therapy services, speech and audiology services, prosthetic devices such as glasses and hearing aids, skilled nursing home services for persons under the age of 21, intermediate care facility services, and clinic services.

The Federal law requires that providers be reimbursed directly for services provided to eligible recipients through what is known as a vendor payment system. It also requires that States pay for inpatient hospital care on the basis of reasonable cost, and allows them to establish rates at which other providers will be paid. Federal funds are authorized to reimburse States for their expenditures. Federal cost sharing ranges from 50 percent to 83 percent. The percentage depends on the State's per capita income, with poorer States receiving the higher percentages.

In terms of people served and money spent, Medicaid has grown astronomically. Approximately 19 million persons received title XIX services in 1971, and the total is expected to rise to over 20 million in 1972. Of course, the program's costs have risen too. Medical assistance expenditures for all Federal-State programs for the poor rose from $1.7 billion in 1966 to $6.2 billion in 1971, with the Federal share increasing from $200 million in 1966 to an estimated $3.2 billion in 1971. To some extent, these increased expenditures reflect the effects of inflation, but primarily they can be accounted for by the larger number of persons served and the greater quantity and variety of services furnished.

How does all this relate to the developmentally disabled? The original title XIX legislation passed in 1965 and subsequent amendments up until December 1971, contained no specific reference to the developmentally disabled or to the mentally retarded. However, in response to questions which arose in the States, HEW specifically spelled out for the mentally retarded its general policy: the retarded were to be considered eligible for title XIX services on the same basis as any other potentially eligible person. A State was expected to provide the services in its title XIX plan to eligible retarded persons the same as it provided such services to other eligible recipients. This continues to be HEW policy except for new legislation effective last year, which I shall discuss later.

The earliest claims by States for Federal sharing in the area of developmental disabilities came from institutions or parts of institutions for the mentally retarded classed as medical facilities, either hospitals or skilled nursing homes, usually the latter. By 1971, about 18 States were making such claims totalling approximately $125 million in Federal matching funds during that year.

In regard to coverage of the developmentally disabled, a survey conducted in 1970 of persons receiving Aid to the Disabled found that 138,100 individuals, or 16.0% of the AD caseload, had primary diagnoses of mental deficiency. In addition, 2.5% suffered from epilepsy and 1.8% from cerebral palsy. Another 50,800 persons, or 5.9%, of the caseload has these conditions as secondary diagnoses. More than ¼ of all persons receiving disability payments had primary or secondary diagnoses of epilepsy, cerebral palsy, or mental retardation. When the primary diagnostic category was expanded to special learning disabilities or mental deficiency, the figures rose to 245,600 persons and 28.6% of the AD caseload.

Because diagnoses are not required, reliable data on other categories of assistance are more difficult to obtain. In the same 1970 survey, it was found that 71,700 persons, or 3.5% of the old age assistance caseload, was reported as having special learning disabilities or mental deficiency. In a similar survey in 1967 of children on Aid to Families with Dependent Children, 89,000 children, or 2.3% of the AFDC caseload, were positively identified as being mentally retarded. However, these figures are believed to be considerably below the actual incidence of mental retardation among AFDC children because of incomplete reporting and the existence of many undiagnosed cases. The data also virtually excluded children placed in institutions for the retarded.

I shall now turn to the new legislation, or perhaps by now the not so new legislation, which I have mentioned twice already. Public Law 92-223, signed into law by the President on December 28,1971, and effective January 1, 1972, has the potential for having a substantial direct impact on institutional care for the developmentally disabled, and indirectly, we hope, on noninstitutional and community services.

This legislation transferred intermediate care facility services from Title XI of the Social Security Act to Title XIX as an optional service a State may include in its Medicaid program. ICF's are institutions designed to provide a protected environment for persons whose health and other related needs require constructive supervision in an institutional setting. They provide a range of services to help the infirm maintain maximum physical, mental, and social functioning as long as possible.

Most importantly for us here today, P.L. 92-223 enables States to include in their title XIX plan intermediate care facility services provided in institutions for mentally retarded or for persons with related conditions (which HEW is defining as epilepsy, cerebral palsy and other conditions covered by the Developmental Disabilities Act). Principal provisions in the law relating to participation by these institutions as intermediate care facilities are:

1. The institution must provide health or rehabilitative services for the mentally retarded.

2. Individuals participating in the program must be receiving active treatment in such an institutional program.

3. The State or political subdivision responsible for the participating institution must agree not to reduce non-Federal expenditures for patients in such institutions.

The new legislation provides the Secretary of Health, Education, and Welfare with wide authority to establish standards which institutions must meet in order to participate in title XIX. It also requires of the States a program of initial evaluation and periodic review, called independent professional review, of each resident to determine that he needs continued institutional care and is actually receiving the care and services he needs.

Because HEW had no lead time, and because a number of issues raised by the legislation have had to be resolved first, Federal regulations to implement the legislation I have just discussed are still in the process of development. Proposed rule making was in the *Federal Register* on March 5, 1973 and HEW is now reviewing comments received on them.

In developing regulations, we have taken a number of factors into consideration. Among these are the intent of Congress to improve institutional care and services to the mentally retarded and to provide adequate safeguards for Federal funds expended, the President's goal of reducing by one-third the number of retarded persons in institutions, and recommendations by many experts in the field of mental retardation with whom we consulted.

As a result, it has become our goal to design a set of standards and requirements to ensure that the institution provides services adequate to develop maximum independent living capabilities of its residents in order to return them to the community at the earliest possible time. In developing these standards we have attempted, as much as the law permits, to use the developmental model rather than the medical model.

Because there are so many variables and uncertainties, no one is making many specific predictions about how many Federal dollars will be claimed by States for institutional care for the developmentally disabled. However, we certainly expect payments to institutions to be substantially in excess of the $125 million paid in 1971. As of September 1, 1972, 29 States had already included institutions for the retarded in their intermediate care program and a number of other States indicated that they planned to do so.

The impact of this new title XIX service then stems from two directions: The need to meet initially moderate Federal standards to qualify for title XIX and the new availability of large sums of Federal funds which the States will be expected to use to further upgrade institutional care and services. And as institutions prepare more of their residents for release, more pressure will develop to encourage non-institutional and community services for the developmentally disabled.

One other title XIX service which should be singled out for comment here is early and periodic screening, diagnosis and treatment of children. This service, mandatory on States participating in Title XIX, should prove highly useful in identifying developmentally disabled children among the poor. Early and periodic screening has been given top priority in HEW this year to insure that it is properly implemented.

The Social and Rehabilitation Service, the agency in HEW which has responsibility for all welfare assistance programs, has set as one of its top priorities a 5-year goal for the "deinstitutionalization" of persons in institutions for the mentally retarded. SRS is now developing objectives to assist in meeting this goal and fitting it into its goals for the new legislation on intermediate care facility services.

You may have gotten the impression from my earlier comments about title XIX that State Medicaid programs vary a good deal in their eligibility standards, services covered, and so on—and you are correct. If you want to know more about what your individual State provides under title XIX, I suggest you get in touch with the agency in your State responsible for the Medicaid program, generally the Social Services or Welfare Department, the Health Department, or a combined State Health and Social Services agency. They will be able to give you all the details about your State program.

In our workshop discussions today and tomorrow, I would like to suggest several things for us to consider. For example, in regard to eligibility requirements for programs of Aid to the Disabled, some States still severely restrict coverage for the mentally retarded or exclude them altogether. Some other questions to think about are: How may title XIX increase its influence to improve the quality of care and efficient delivery of health services?

What steps are necessary to insure that eligible developmentally disabled persons receive the services they need that are currently available under State plans? While more poor people today are receiving medical care than they did prior to title XIX, in visits to States SRS staff has found that some eligible needy are not receiving care to which they are entitled.

How may organizations and individuals working with the developmentally disabled assist Medicaid-eligible patients to get the care to which they are entitled?

What can we do to encourage States to provide more comprehensive services to the developmentally disabled? Title XIX encompasses a wide range of outpatient services not always included in State Medicaid plans. Since new title XIX funds have become available to upgrade institutional services, States may now be able to use their own funds earmarked for this purpose to develop other resources for the developmentally disabled.

With large new amounts of Federal grants going to States for a companion SRS Social Services program, how may we coordinate the two programs to develop a set of comprehensive services for the developmentally disabled?

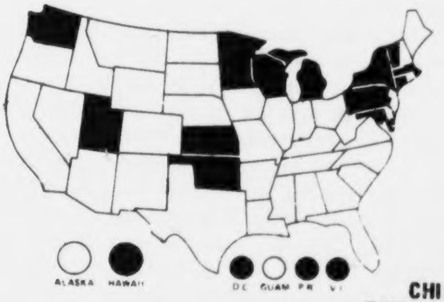
Finally, what will H.R. 1, recently signed into law by the President as P.L. 92-603, mean for us here? It is difficult to say much on the basis of an early analysis of so much new legislation. Aside from making family planning services mandatory in a State title XIX plan and providing penalties for States which do not properly implement early and periodic screening, diagnosis and treatment, there does not appear to be much under title XIX specifically applicable to services for the developmentally disabled. However, P.L. 92-603 has introduced a large number of new requirements, particularly eligibility, administrative and review procedures, which will have a direct impact on the developmentally disabled.

Perhaps the most significant change made by P.L. 92-603 is the replacement, effective January 1, 1974, of the present State programs of aid to the aged, blind and disabled with a new Federalized program of "Supplemental Security Income" for these categories. This is not a subject of this workshop, but might be worth mentioning briefly because it may affect eligibility for title XIX. Among other things the new Supplemental Security Income Program establishes a nationally uniform definition for the disabled which will probably be more liberal than the ones in use in some States, not as liberal in others. The definition also specifically provides for coverage of children under age 18. Much more will be forthcoming concerning the amendments in P.L. 92-603 and I suggest you keep abreast of developments.

In conclusion, as our group discussions have pointed out, State and local Councils have a responsibility to know what is in their respective State title XIX plans and what is going on in the State. This is necessary if the Councils are to be effective in assuring that the developmentally disabled receive services to which they are entitled. It is also necessary if the Councils are to effectively exercise their influence in efforts to broaden coverage under title XIX. And in this day of tight State budgets it is important to utilize all the clout and justification available to convince States to expand their Medicaid program. Title XIX is potentially the biggest source of Federal funds available to a State in upgrading care and services for the developmentally disabled.

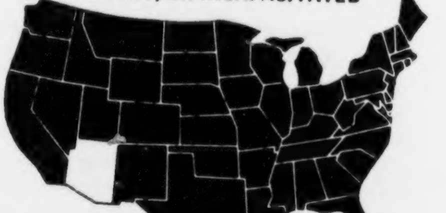
MEDICAID CHILDREN Who are they?

ALL FINANCIALLY ELIGIBLE CHILDREN

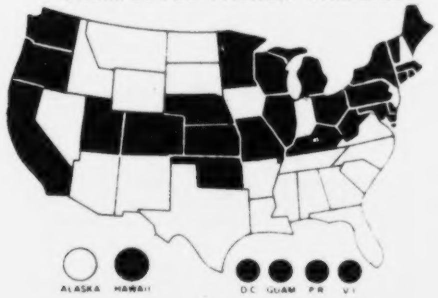


Appendix B

CHILDREN IN FINANCIALLY ELIGIBLF FAMILIES WITH AT LEAST ONE PARENT DEAD, ABSENT, OR INCAPACITATED



CHILDREN IN FINANCIALLY ELIGIBLE "UNEMPLOYED-FATHER" FAMILIES


ALASKA
HAWAII
DC
GUAM
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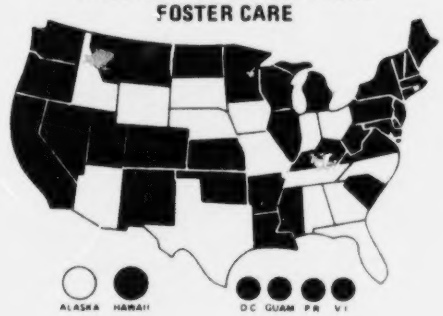
VI

CHILDREN IN PUBLICLY AIDED FOSTER CARE


ALASKA
HAWAII
DC
GUAM
PR
VI

UNITED STATES DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE

Social and Rehabilitation Service **Medical Services Administration**

data as of June 30, 1971 msa-804-71 public information office

Appendix A

MEDICAID SERVICES STATE BY STATE,
SEPTEMBER 1, 1972

BASIC REQUIRED MEDICAID SERVICES: Every Medicaid program must cover at least these services for at least everyone receiving federally supported financial assistance: inpatient hospital care; outpatient hospital services; other laboratory and X-ray services; skilled nursing home services and home health services for individuals 21 and older; early and periodic screening, diagnosis, and treatment for individuals under 21; and physicians' services. Federal financial participation is also available to States electing to expand their Medicaid programs by covering additional services and/or by including people eligible for medical but not for financial assistance. For the latter group States may offer the services required for financial assistance recipients or may substitute a combination of seven services.

Services provided only under the Medicare buy-in or the screening and treatment program for individuals under 21 are not shown on this chart.

Definitions and limitations vary from State to State. Details are available from local welfare offices and State Medicaid agencies.

- ● offered for people receiving federally supported financial assistance
- + offered also for people in public assistance categories[2] who are financially eligible for medical but not for financial assistance

FMAP[3]	BASIC* REQUIRED MEDICAID SERVICES SEE ABOVE		Additional services for which Federal financial participation is available to States under Medicaid.																	
			Clinic services	Prescribed drugs	Dental services	Prosthetic devices	Eyeglasses	Private duty nursing	Physical therapy and related services	Other diagnostic, screening, preventive and rehabilitative services	Emergency hospital services	Family planning services	Skilled nursing home services for patients under 21	Optometrists' services	Podiatrists' services	Chiropractors' services	Care for patients 65 or older in institutions for mental diseases	Care for patients 65 or older in institutions for tuberculosis	Institutional services in intermediate care facilities	
78	●	Alabama		●			●				●			●				●	●	AL
50	●	Alaska									●	●								AK
64		Arizona																		AZ
79	●	Arkansas			●						●					●	●	●	● 4/	AR
50	+	California	+	+	+	+	+	+	+		+	+	+	+	+	+	+	+	+ 4/	CA
58	●	Colorado		●		●					●	●	●		●		●		● 4/	CO
50	+	Connecticut	+	+	+	+	+	+	+	+		+	+	+	+	+	+			CT
50	●	Delaware	●	●		●			●	●		●			●		●	●		DE
50	+	D.C.	+	+		+	+		+		+	+	+	+	+		+	+	+ 4/	DC
61	●	Florida		●							●	●					●	●	● 4/	FL
70	●	Georgia		●								●	●		●				● 4/	GA
50	+	Guam	+	+	+	+	+					+	+	+						GU
51	+	Hawaii	+	+	+	+	+		+	+	+	+	+	+					+	HI
72	●	Idaho		●							●	●	●	●	●	●	●		● 4/	ID
50	+	Illinois	+	+	+	+	+	+	+	+	+	+	+	+	+		+	+	+ 4/	IL
55	●	Indiana	●	●	●	●	●	●	●	●	●	●	●	●	●	●			●	IN
58	●	Iowa		●	●	●	●		●		●	●	●	●	●	●				IA
59	+	Kansas	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+ 4/	KS
73	+	Kentucky		+	+				+	+		+	+				+	+	●	KY
73	●	Louisiana	●	●		●				●	●						●	●	● 4/	LA
69	●	Maine	●	●		●	●	●	●	●	●	●	●	●	●	●	[illegible]		●	ME
50	+	Maryland	+	+	+	+	+		+	+	+	+		+	+		+	+	+	MD
50	+	Massachusetts	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	MA

4/ optional service, effective 1-1-72. States may at their option include

50	+	Michigan		+					+		+	+	+		+	+	+	+	+ 4/	MI
57	+	Minnesota	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+ 4/	MN
83	●	Mississippi		●	●		●				●		●	●				●		MS
60	●	Missouri		●	●							●					●	●		MO
67	●	Montana	●	●	●	●	●	●	●		●	●	●	●			●	●	● 4/	MT
58	+	Nebraska	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+ 4/	NB
50	●	Nevada	●	●	●	●	●	●	●	●	●	●		●	●		●	●	●	NV
59	+	New Hampshire	+	+	+	●	+	●	●	●	+	+	+	+	+	+				NH
50	●	New Jersey	●	●	●	●	●		●	●	●	●	●	●	●		●	●	● 4/	NJ
73	●	New Mexico	●	●	●	●	●	●	●		●	●	●	●	●				● 4/	NM
50	+	New York	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+ 4/	NY
73	+	North Carolina		+	+	+	+				+	+		+	+	●	+	+		NC
71	+	North Dakota	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+		ND
54	●	Ohio	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●		● 4/	OH
69	+	Oklahoma			+								+				+		+ 4/	OK
57	●	Oregon	●	●	●	●	●	●		●	●	●	●	●	●	●	●	●	● 4/	OR
55	+	Pennsylvania	+	●	●	●	+					●	+	+	●	+	+		● 4/	PA
50	+	Puerto Rico	+	+	+				+	+	+	+						+		PR
50	+	Rhode Island		+	+	+	+					+		+	+		+		● 4/	RI
78	●	South Carolina	●	●							●		●				●	●	● 4/	SC
70	●	South Dakota	●			●	●		●		●	●	●	●	●	●			●	SD
74	●	Tennessee		●							●	●					●	●	● 4/	TN
65	●	Texas		●							●			●	●	●	●	●	● 4/	TX
70	+	Utah	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+		+ 4/	UT
65	+	Vermont	+	+		+			+		+	+	+		+		+		+	VT
50	+	Virgin Islands	+	+	+	+	+		+			+								VI
64	+	Virginia	+	+		+	+		+		+	+	+	+	+		+	+	+ 4/	VA
50	+	Washington	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+ 4/	WA
77	●	West Virginia	●	●	●	●	●	●	●	●		●	●	●	●	●	●	●		WV
56	+	Wisconsin	+	+	+	●	●	●	+	●	+		●	●	+		+		+ 4/	WI
63	●	Wyoming																	●	WY
●	26	●	13	23	13	17	14	10	12	11	21	20	16	16	16	11	17	15	23	
+	27	+	22	25	22	20	21	11	21	14	20	24	21	20	20	13	22	16	17	
	53	Total	35	48	35	37	35	21	33	25	41	44	37	36	36	24	39	31	40	

Intermediate Care Facilities (ICF): P.L. 92-223 transferred the ICF program to Medicaid (Title XIX) as an institutions for the mentally retarded, both public and private. See footnote four.

1/ Data from Regional Office reports of characteristics of State programs

2/ People qualifying as aged, blind, disabled, or members of families with dependent children (usually families with at least one parent absent or incapacitated)

3/ FMAP - Federal Medical Assistance Percentage: Rate of Federal financial participation in a State's medical vendor payment expenditures on behalf of individuals and families eligible under Title XIX of the Social Security Act. Percentages, effective from July 1, 1971, through June 30, 1973, are rounded

4/ Including ICF services in institutions for the mentally retarded

UNITED STATES DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE Social and Rehabilitation Service Medical Services Administration

Office of Program Planning and Evaluation

(SRS) -73- 24801 public information office

Appendix C

MEDICAID

Single State Agencies
State Medical Assistance Units

Alabama

Dr. Ira L. Myers, State Health Officer, Alabama Department of Public Health, 304 Dexter Avenue, Montgomery, AL 36104

Dr. Paul I. Robinson, Director, Medical Services Administration, Alabama Department of Public Health, 304 Dexter Avenue, Montgomery, AL 36104

Alaska

Mr. Frederick McGinnis, Commissioner, Department of Health & Social Services, Pouch H, Juneau, AK 99801

Mr. Lawrence Sullivan, Acting Director, Division of Medical Assistance, Department of Health & Social Services, Pouch H, Juneau, AK 99801

Arizona

No Medicaid Program

Arkansas

Dr. Dalton Jennings, Commissioner, Arkansas Social Services, State Capitol Mall, P.O. Box 1437, Little Rock AR 72201

Mr. Allen Cooper, Medical Care Division, Arkansas Social Services, State Capitol Mall, P.O. Box 1437, Little Rock AR 72201

California

Mr. Dwight Geduldig, Director, Department of Health Care Services, Human Relations Agency, 714 P Street, Office Building No. 8, Sacramento CA 95814

(Single State Agency and Medical Assistance Unit are the same)

Colorado

Mr. Con Shea, Director, Department of Social Services, 1575 Sherman Street Denver, CO 80203

Miss Charline Birkins, Director of Medical Services, Department of Social Services, 1575 Sherman Street, Denver CO 80203

Connecticut

Mr. Nicholas Norton, Commissioner, State Welfare Department, 1000 Asylum Avenue, Hartford CT 06105

Mr. James F. Morrison, Director of Health Services, State Welfare Department, 1000 Asylum Avenue, Hartford CT 06105

Delaware

Mr. J. D. White, Acting Secretary, Department of Health and Social Services, P.O. Box 309, Wilmington DE 19899

Dr. Miklos T. Larzar, Director, Division of Social Services, Department of Health and Social Services, P.O. Box 309, Wilmington DE 19899

Miss Mary Lee Berry, Chief, Medical Social Work Consultant, Division of Social Services, Department of Health and Social Services, P.O. Box 309, Wilmington DE 19899

District of Columbia

Mr. Joseph P. Yeldell, Director, Department of Human Resources, District Building, Room 406, Washington DC 20004

Dr. William J. Washington, Deputy Director, Department of Human Resources, 14th and E Streets, N.W., Washington DC 20004

Florida

Mr. Emmett S. Roberts, Secretary, Department of Health and Rehabilitation Services, IBM Branch Office Building, 660 Apalachee Parkway, Tallahassee FL 32304

Mr. E. Douglas Endsley, Director, Division of Family Services, Department of Health and Rehabilitation Services, P.O. Box 2050, Jacksonville FL 32203

Mr. Wright Hollingsworth, Chief, Bureau of Medical Services, Department of Health and Rehabilitation Services, P.O. Box 2050, Jacksonville FL 32203

Georgia

Mr. Richard M. Harden, Commissioner, Georgia Department of Human Resources, State Office Building, Atlanta GA 30334

Mrs. Betty Bellairs, Director, Division of Benefits Payments, Georgia Department of Human Resources, State Office Building, Atlanta GA 30334

Guam

Mr. Franklin Cruz, Department of Public Health and Social Services, Government of Guam, P.O. Box 2816, Agana GU 96910

Mr. Pedro Santos, Director, Medical Care Services, Department of Public Health and Social Services, Government of Guam, P.O. Box 2816, Agana GU 96910

Hawaii

Mr. Myron B. Thompson, Director, Department of Social Services and Housing, P.O. Box 339, Honolulu HI 96809
Attention: Mr. Edwin B. L. Tam, Administrator, Division of Public Welfare

Mr. Robert Millar, Medical Care Administrator, Division of Public Welfare, Department of Social Services and Housing, P.O. Box 339, Honolulu HI 96809

Idaho

Dr. John Marks, Commissioner, Idaho Social and Rehabilitation Services, P.O. Box 1189, Boise ID 83701

Mr. Kenneth V. Thomas, Director of Medical Assistance, Idaho Social and Rehabilitation Services, P.O. Box 1189, Boise ID 83701

Illinois

Director, Department of Public Aid, 618 East Washington Street Springfield IL 62706

Dr. Bruce A. Flashner, Medical Director, Division of Medical Services, Department of Public Aid, Room 900, 209 West Jackson Boulevard, Chicago IL 60606

Mr. Robert G. Wessell, Chief, Medical Administration, Division of Medical Services, Department of Public Aid, 425 South Fourth Street, Springfield IL 62706

Indiana

Mr. Wayne Stanton, Administrator, Indiana State Department of Public Welfare, 100 North Senate Avenue, Room 701, Indianapolis IN 46204

Mr. Edmund Mesterhorn, Director, Medical Services Division, Indiana State Department of Public Welfare, 100 North Senate Avenue, Room 701, Indianapolis IN 46204

Iowa

Mr. James N. Gillman, Commissioner, Iowa Department of Social Services, Lucas State Office Building, Des Moines IA 50319

Dr. Elmer Smith, Director of the Bureau of Medical Services, Iowa Department of Social Services, Lucas State Office Building, Des Moines IA 50319

Kansas

Dr. Robert C. Harder, State Director of Social Welfare, State Department of Social Welfare, State Office Building, Topeka KS 66612

Mr. William A. Newman, Director, Division of Medical Services, State Department of Social Welfare, State Office Building, Topeka KS 66612

Kentucky

Mrs. Gail Huecker, Commissioner, Department of Economic Security, Capitol Annex, Frankfort KY 40601

Mr. Jack Wadell, Director, Division of Medical Assistance, Department of Economic Security, Capitol Annex, Frankfort KY 40601

Louisiana

Mr. Garland L. Bonin, Commissioner, Department of Public Welfare, P.O. Box 44065, Baton Rouge LA 70804

Dr. Neal D. Blanchard, Director, Medical Services Division, Department of Public Welfare, P.O. Box 44065, Baton Rouge LA 70804

Maine

Dr. Dean H. Fisher, Commissioner, Department of Health and Welfare, State House, Augusta ME 04330

Dr. Gilbert E. Marcotte, Director, Bureau of Medical Care, Department of Health and Welfare, State House, Augusta ME 04330

Maryland

Dr. Neil Solomon, Secretary, Department of Health and Mental Hygiene, 301 West Preston Street, Baltimore MD 21201

Mr. J. C. Eshelman, Director, Division of Medical Care Programs Administration, Department of Health and Mental Hygiene, 301 West Preston Street, Baltimore MD 21201

Massachusetts

Mr. Steven A. Minter, Commissioner, Department of Public Welfare, 600 Washington Street, Boston MA 02111

Assistant Commissioner for Medical Care, Department of Public Welfare, 600 Washington Street, Boston MA 02111

Mr. John F. Mungovan, Commissioner, Massachusetts Commission for the Blind, 39 Boylston Street, Boston MA 02116

Michigan

Mr. R. Bernard Houston, Director, Michigan Department of Social Services, Commerce Center Building, 300 South Capitol Avenue, Lansing MI 48926

Mr. Stuart M. Paterson, Jr., Deputy Director, Medical and Management Information System, Michigan Department of Social Services, 300 South Capitol Avenue, Lansing MI 48926

Minnesota

Mrs. Vera L. Likins, Commissioner, Minnesota Department of Public Welfare, Centennial Office Building, 658 Cedar Street, St. Paul MN 55101

Mr. L. Irving Peterson, Supervisor, Public Medical Assistance Programs, Minnesota Department of Public Welfare, Centennial Office Building, 658 Cedar Street, St. Paul MN 55101

Mississippi

Dr. Alton B. Cobb, Director, Mississippi Medicaid Commission, Room 313, Dale Building, 2906 North State Street, Jackson MS 39216
(Single State Agency and Medical Assistance Unit are the same)

Missouri

Mr. Bert Shulimson, Director, Division of Welfare, Department of Public Health & Welfare, Broadway State Office Building, Jefferson City MO 65101

Mr. T. E. Singleton, Chief, Bureau of Medical Services, Department of Public Health & Welfare, Broadway State Office Building, Jefferson City MO 65101

Montana

Mr. Theodore P. Carkulis, Administrator, Department of Social and Rehabilitation Services, P.O. Box 1723, Helena MT 59601

Mr. William Ikard, Director of Medical Services, Department of Social and Rehabilitation Services, P.O. Box 1723, Helena MT 59601

Nebraska

Mr. Lawrence L. Graham, Director, State Department of Public Welfare, 1526 K Street, 4th Floor, Lincoln NB 68508

Mr. Donald Hogg, Chief, Medical Services, State Department of Public Welfare, 1526 K Street, 4th Floor, Lincoln NB 68508

Nevada

Mr. George E. Millar, Administrator, Welfare Division, Department of Health, Welfare and Rehabilitation, 201 South Fall Street, Carson City NV 89701

Mr. Minor L. Kelso, Chief, Medical Services, Welfare Division, Department of Health, Welfare and Rehabilitation, 201 South Fall Street, Carson City NV 89701

New Hampshire

Mr. Gerard J. Zeiller, Commissioner, Department of Health and Welfare, State House Annex, Concord NH 03301

Dr. Robert W. Kaschub, Assistant Director for Medical Services, Division of Welfare, Department of Health and Welfare, State House Annex, Concord NH 03301

New Jersey

Mr. Lloyd W. McCorkle, Commissioner, Department of Institutes and Agencies, P.O. Box 1237, 135 West Hanover, Trenton NJ 08625

Mr. William J. Jones, Director, Division of Medical Assistance and Health Services, New Jersey Department of Institutes and Agencies, P.O. Box 2486, 36 West State Street, Trenton NJ 08625

New Mexico

Mr. Richard W. Heim, Executive Director, New Mexico Health and Social Services Department, P.O. Box 2348, Santa Fe NM 87501

Dr. Robert Patten, Chief, Division of Medical Services, New Mexico Health and Social Services Department, P.O. Box 2348, Santa Fe NM 87501

New York

Mr. Abe Lavine, Commissioner, State Department of Social Services, P.O. Box 1740, Albany NY 12201

Mr. Bernard Shapiro, Deputy Commissioner, New York State Department of Social Services, 1450 Western Avenue, Albany NY 12203

North Carolina

Dr. Jacqueline R. Westcott, Commissioner, Office of Social Services, State Department of Human Resources, P.O. Box 2599, Raleigh NC 27602

Mr. Emmett Sellers, Director, Division of Medical Services, State Department of Social Services, P.O. Box 2599, Raleigh NC 27602

North Dakota

Mr. T. N. Tangedahl, Executive Director, Public Welfare Board of North Dakota, Capitol Building, Bismarck ND 58501

Mr. Richard Myatt, Administrator, Medical Program, Public Welfare Board of North Dakota, Capitol Building, Bismarck ND 58501

Ohio

Mr. Charles W. Bates, Director, Ohio Department of Public Welfare, 408 Town Street, Columbus OH 43215

Mr. Frederick J. Zuber, Chief, Division of Medical Assistance, Ohio Department of Public Welfare, 340 East Broad Street, Columbus OH 43215

Oklahoma

Mr. L. E. Rader, Director, Department of Institutes, Social and Rehabilitation Services, P.O. Box 25352, Oklahoma City OK 73125

Dr. Bertha Levy, Director, Medical Services, Division, Department of Institutions, Social and Rehabilitation Services, P.O. Box 25352, Oklahoma City OK 73125

Oregon

Mr. Jacob B. Tanzer, Director, Department of Human Resources, 318 Public Service Building, Salem OR 97310

Dr. D. E. Domke, Medical Director, Medical Assistance Section, Department of Human Resources, 318 Public Service Building, Salem OR 97310

Pennsylvania

Mrs. Helene Wohlgemuth, Secretary, State Department of Public Welfare, Health and Welfare Building, Harrisburg PA 17120

Mr. Charles Cubbler, Commissioner, Medical Services Administration, Department of Public Welfare, Health and Welfare Building, Harrisburg PA 17120

Mr. Glenn Johnson, Director, Bureau of Medical Assistance, Department of Public Welfare, Health and Welfare Building, Harrisburg PA 17120

Puerto Rico

Dr. Jose Alvarez de Choudens, Secretary of Health, Department of Health, P.O. Box 9342, Santurce PR 00908

Mr. Luis Cruz Cuevas, Director, Medical Assistance Program, Department of Health, P.O. Box 9342, Santurce PR 00908

Rhode Island

Mr. John J. Affleck, Director, Department of Social and Rehabilitation Services, Aime J. Forand Building, 600 New London Avenue, Cranston RI 02920

Dr. P. Joseph Pesare, Medical Director, Department of Social and Rehabilitation Services, Aime J. Forand Building, 600 New London Avenue, Cranston RI 02920

South Carolina

Dr. R. Archie Ellis, Commissioner, State Department of Public Welfare, P.O. Box 1520, Columbia SC 29202

Dr. William T. Leslie, Director, Division of Medical Assistance, State Department of Public Welfare, P.O. Box 1520, Columbia SC 29202

South Dakota

Mr. John E. Madigan, Director, Department of Public Welfare, State Office Building, Pierre SD 57501

Mr. Ervin Schumacher, Supervisor, Public Assistance Medical Program, Department of Public Welfare, State Office Building, Pierre SD 57501

Tennessee

Dr. Eugene W. Fowinkle, Commissioner, State Department of Public Health, 344 Cordell Hull Building, Nashville TN 37219

Dr. E. Conrad Shackleford, Jr., Director, Bureau of Medical Care Services, State of Tennessee Department of Public Health, 344 Cordell Hull Building, Nashville TN 37219

Texas

Mr. Raymond W. Vowell, Commissioner, State Department of Public Welfare, John H. Reagan Building, Austin TX 78701

Dr. Philip A. Gates, Assistant Commissioner for Medical Administration, Department of Public Welfare, John H. Reagan Building, Austin TX 78701

Utah

Mr. Paul Rose, Director, Department of Social Services, 231 East 4th Street, South, Salt Lake City UT 84111

Mr. Frank Dix, Chief, Medical Services Section, Department of Social Services, 231 East 4th Street, South, Salt Lake City UT 84111

Vermont

Mr. Paul R. Philbrook, Acting Commissioner, Department of Social Welfare State Office Building, Montpelier VT 05602

Mr. Elmo A. Sassorossi, Director of Medical Care, Department of Social Welfare, State Office Building, Montpelier VT 05602

Virginia

Dr. Mack I. Shanholtz, Commissioner, State Department of Health, 109 Governor Street, Richmond VA 23219

Dr. Edwin Brown, Director, Medical Assistance Program, State Department of Health, 109 Governor Street, Richmond VA 23219

Virgin Islands

Dr. Eric L. O'Neal, Commissioner of Health, Virgin Islands Department of Health, Charlotte Amalie, St. Thomas VI 00801

Mrs. Irma Revilla, Director, Bureau of Health, Virgin Islands Department of Health, Charlotte Amalie, St. Thomas VI 00801

Washington

Dr. Wallace Lane, Assistant Secretary, State Department of Social and Health Services, P.O. Box 1162; Olympia WA 98501

Dr. Robert T. Hall, Chief, Office of Medical Care, State Department of Social and Health Services, P.O. Box 1162, Olympia WA 98501

West Virginia

Mr. Edwin F. Flowers, Commissioner, Department of Welfare, 1900 Washington Street, East, Charleston WV 25305

Mrs. Helen Condry, Director, Division of Medical Care, Department of Welfare, 1900 Washington Street, East, Charleston WV 25305

Wisconsin

Mr. John Murphy, Director of Medical Services, Division of Family Services, Wisconsin Department of Health and Social Services, One West Wilson Street, Madison WI 53702

Mr. Frank J. Newgent, Administrator, Division of Family Services, Wisconsin Department of Health and Social Services, One West Wilson Street, Madison WI 53702

Wyoming

Dr. Lawrence J. Cohen, Administrator, Division of Health and Medical Services, Department of Health and Social Services, State Office Building, Cheyenne WY 82001

Mr. Ernest A. Rumpf, Director, Medical Assistant Service, Division of Health and Social Services, Department of Health and Social Services, State Office Building, Cheyenne WY 82001

U.S. DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE
Social and Rehabilitation Service Medical Services Administration
april 1973 msa-73-24808 public information office

Services Available to the Developmentally Disabled Through the Mental Health Component of Comprehensive Health Planning

Nathan Sloate

This article is a summary of the presentation and discussion on Services Available to the Developmentally Disabled Through the Mental Health Component of Comprehensive Health Planning held at the National Conference on Developmental Disabilities, 1972. The subject was introduced by a reference to common meeting ground provided by public health for the merger of services for physical health and illness, mental health and impairment, and developmental disabilities, including mental retardation. The major points of convergence were seen as the emphasis on community-wide environmental factors, including the impact on family relationships, intergroup relations, the influence of social institutions and the broadening range and growing similarity of the constellation of professional disciplines involved in direct services and planning. Reference was made to the historic movement from institution-centered to community-centered programs. Hospitals alone are no longer regarded as the hub for treatment and planning. Mental retardation is no longer seen as a "treatment" but as a condition.

The interdisciplinary approach is coming to the fore. Lawyers, architects and new careerists are examples of the broadening range of staff necessarily involved in the totality of services required for total programs.

Also in the picture are the programs and fiscal realities which result in budget austerity and emphasis on program results. Greater accountability is being demanded by administrators, legislators and the public alike. Citizen involvement has become stronger to better ensure consumer choice.

In examining the common ground that exists for reinforcing the program objectives of mental health and developmental disabilities, we note that the mentally ill and the mentally retarded are still linked in the program structures of many states. There is an intermingling in legislation and programing for mental illness, developmental disabilities and health in such programs as medicare, medicaid, revenue sharing, health maintenance organizations, community mental health services and comprehensive health planning. These provide opportunities for need centered, family centered and community centered approaches to collaborative endeavors.

Community mental health centers can help close the gap between mental health research findings and prevention, as for example in genetic counseling. They can help cope with general impairment of adaptive behavior. Through rehabilitation services, they can help maintain and support in the community those who no longer require institutional care. Through crisis intervention and support, families can be strengthened to lessen the impact of retardation. Through participation in community planning, the center could arrive at a better understanding of what it could contribute and provide needed mental health input.

Although we have moved from a one-choice, institutional model to a broad community spectrum, mostly within the past decade, we need stronger underpinnings for these new beginnings. That community mental health centers provide a low proportion of services may be due in part to the uncertainty in the minds of parents as to the mental health commitment. "Where were you when we needed you" they might well be thinking. The community mental health centers for their part have not encouraged more services for this group. This unproductive equilibrium can be broken only by a renewed recognition on either or both sides that here is a useful resource.

State mental health authorities with their extensive programs moving into the arena of the community inevitably become drawn into community planning. Coalition planning with this powerful resource could well achieve more appropriate utilization of services.

The number one program priority of the National Institute of Mental Health is children. This applies to its total program of research, training, and services. Its general objectives are congruent with those for the mentally retarded. Within its existing limited resources it will respond to demands for its programs. But for respectable strides forward, additional resources are needed.

Some of the issues presented by the topic writer and resources members for discussion included the following:

1. Given the existing limitations of the partnership for health and mental health system, what practical steps could be taken to further collaborative enterprise in behalf of the developmentally disabled at the service or consumer level?

2. How can trust between the mental health, comprehensive health planning and developmental disabilities systems be enhanced in the interests of the mentally retarded?

3. What can be done to strengthen the commitment of the mental health system in serving the developmentally disabled?

4. How can the constituency of the developmentally disabled best work in coalition with mental health agencies to build stronger and more effective mental health services in behalf of the retarded?

5. In what ways can mental health and comprehensive health planning contribute to the national commitment to reduce by half the occurrence of mental retardation in the United States before the end of the century and to enable one-third of the more than 200,000 retarded persons in public institu-

tions to return to useful lives in the community.

Included in the discussion were the following points:

How do we strike a reasonable balance between the so-called categorical approach and more generalized programs? The dilemma created by specialized programs is that the full range of generalized resources may be cut off from the recipient. It was agreed that planning coalitions were essential to keep open the availability of generic services to the developmentally disabled.

There was general recognition that there was only a slight point of convergence between the comprehensive health planning program and that of the developmentally disabled because of different priorities, insufficient funds and different program emphasis. Programing for the developmentally disabled only partly falls under the health rubric.

It is of major importance, however, that the developmentally disabled not be excluded from the benefits of health and mental health programs simply by virtue of their disability. Thus, a family with a retarded member would not be excluded from receiving needed mental health services, even though that retarded person may receive other benefits from other programs.

Representatives from the various states reported a wide variety of administrative structures, ranging from programs operating out of the governors' offices to token arrangements. No single pattern of organization seemed to predominate. Relatively little is known by people in the developmental disability programs about the comprehensive planning mechanisms and vice versa, so they have very little to do with one another. One suggestion for overcoming this deficiency was to try to secure overlapping representation on the advisory committees.

There was some feeling that closer working relationships could be better achieved by strengthening incentives, particularly decisions involving allocation of funds. Programs discriminating against the developmentally disabled should be scrutinized with this in mind. Generic agencies should encourage staff interest in serving the developmentally disabled by strengthening reward systems through training and administrative procedures.

It was agreed that comprehensive health planning may be seen as an opportunity to serve the developmentally disabled.

A recommendation was made in one session that the National Institute of Mental Health use its resources to encourage greater availability of mental health services to the mentally disabled.

Services Available to the Developmentally Disabled Through Titles IV and XVI Of the Social Security Act

Jerry Turem

INTRODUCTION

It is always disheartening to begin a paper when one knows that everything he has to say may be changed before he's finished. Such is the case in this paper on the benefits available to the Developmentally Disabled through Titles IV and XVI of the Social Security Act. These Titles have had two major changes as a result of legislation passed by the Congress and signed by the President just prior to the election. The Revenue Sharing Bill has provision for an expenditure ceiling on public social services through the titles we are to discuss. H.R. 1, the Welfare Reform Bill, Social Security Amendments of 1972, has provision to federalize the programs for the aged, blind and disabled known in present context as Title XVI. Because of the recency of these two bills, we are not entirely clear about the full range of implications about what is possible and about the changes which will be taking place.

Consequently this paper will have two major sections. The first section will discuss the Public Assistance Titles and the cash benefits and social services possible under them for the Developmentally Disabled under conditions as they existed prior to the passage and signing of the two recent bills. The second section will attempt to explain the provision of those bills, and what may be happening at the Federal level, as well as implications for the state and local levels.

PRESENT LAW

While the format calls for discussion only of Titles IVA and XVI in the Social Security Act, in fact there are five titles of that Act which deal with programs to provide cash grants and services to individuals or families in need. Title I–Old Age Assistance; Title X–Aid to the Blind and Title XIV–Aid to the Permanently and Totally Disabled, are each independent authorities. Title XVI is a combined program of Aid to the Aged, Blind, and Disabled, and it is a shorthand way of referring to the other three titles. That there is a great deal of latitude with respect to whether the states go for the independent titles or the combined one is indicated by the fact that 18 states have gone for Title XVI–combined program, where the remaining states have gone for the individual programs. As a matter of fact, one state, Nevada, doesn't have a program of Aid to the Permanently and Totally Disabled.

The remaining Title to be discussed, is Title IV, Aid to Families with Dependent Children which has three major subsections, Parts A, B, and C. Part B refers to what used to be known as the Child Welfare Provisions and while there are some potential benefits for the Developmentally Disabled through these provisions, the focus of this discussion is on Part A. Title IVC contains the work incentive program (WIN) and is also not a primary focus. Title IVA represents the bulk of the Aid to Families with Dependent Children cash and service provisions and has been the focus of much discussion over the last 3½ years. It is this program which represents the chief focus of welfare reform. It is also one of the major Titles under which the social services explosion has occurred.

BACKGROUND

To review briefly these public assistance titles, they are grant-in-aid programs from the federal government to the states for state-run welfare programs meeting certain minimal federal standards. These public assistance titles were created during the depression and were intended to provide financial support to the states for their traditional responsibility of providing relief. Initially the programs on the federal level maintained a minimal set of requirements on the theory that public assistance would wither away, and would be returned to the states. While there has always been an underlying principle in the public assistance titles that social services were required, serious funds for the social services were not included until the 1962 Amendments. During testimony on the 1962 Amendments great claims were made for the ability of social services to remove public assistance clients from assistance rolls. The initial thrust of regulations, in the absence of any other standards, created staffing ratios which would allow the states to receive federal matching at the rate of $3.00 for each state dollar, rather than one federal dollar for each state dollar that they were receiving prior to that.

With this favorable federal matching, and the interest of many states in staffing-up to create better control over their assistance caseloads (and hopefully better provision of social services to help people) the welfare bureaucracy in the various states grew from about 40,000 people in the early '60's to over 150,000 by 1969 and close to 200,000 employees during the early 1970's.

In the 1967 welfare amendments, for the first time, authority was granted for state welfare departments and/or their local counterparts to purchase services from nonpublic sources rather than provide them. Traditionally, welfare departments have seen themselves as service providers and if a service–except for foster home care, or occasionally for homemakers–was to be provided, it would be provided through the caseworker who was an employee of the department.

While the 1967 Amendments permitted an alternative way of doing business, it was not until 1969 when one state–California, began to really take hold of the possibilities there. Freely using the authorization to provide services to both former and potential public assistance recipients as well as persons actually receiving assistance, California rapidly found ways to tap into the federal open-ended appropriation. Part of the tap was going to provide services to mentally retarded recipients through the efforts of local associations for retarded children in California. A set of activity centers, some workshops; and, if I understand correctly, some group homes were being supported by what I take to be informal agreements between these services, the State Department of Social Welfare, and some county welfare directors. All agreed that this was an appropriate expenditure of social services funds.

The two largest programs of concern to us would be the Aid to the Permanently and Totally Disabled program, whether it be in Title XIV or as part of Title XVI, and Aid to Families with Dependent Children. The Aid to the Permanently and Totally Disabled program in most states will provide cash payments to Developmentally Disabled individuals over the age of 18. Of course there are many eligibility problems and pitfalls that we will examine in a moment, but this is the only program that is set up to provide cash payments to disabled persons and for which a developmentally disabled person qualifies in most states. In Aid to Families with Dependent Children, many developmentally disabled persons are eligible, but not because of their handicap, rather, the children are eligible because they are deprived of the care and support of at least one parent, by virtue of death, desertion, chronic unemployment, and so forth.

AID TO THE PERMANENTLY AND TOTALLY DISABLED

Under existing state programs, in order to qualify for a cash payment under Aid to the Permanently and Totally Disabled, an individual applicant must be domiciled in the state although durational residence requirements have been outlawed by the Supreme Court. The individual must be at least 18 and in most states, not over 64–since if he were 65 he would be eligible for Old Age Assistance.

The individual must show that he owns real and personal property that is under the limit specified by the given state. Real property used for a home may be owned in thirty states, but in fourteen states it must have a value of less than $7,500 and in five states the value may exceed $7,500 (based on a review of state public assistance plans in effect as of 1969). As reported earlier, only one state–Nevada, does not have an APTD program. Most states' personal property limitations are very modest. An individual may have assets under $500 in 18 states, $500-$749 in 17 states, and the remaining 9 states allow a person to have personal property in excess of $750. Liens on property and various forms of assignments for recovery of assistance payments are required in 25 states. Relative responsibility laws are in effect in a number of states and carry beyond the majority in the case of an individual who applies for assistance payments. An individual must agree to an examination prescribed by the state to demonstrate that he has a permanent and total disability; this may be done by a panel of physicians or psychiatrists of his choice and paid for by the state.

It is difficult to explain state practices and their definitions of permanent and total disability. Prior to passage of H.R. 1, states were allowed to establish their own requirements. Thus the state's definitions could range from a requirement for complete helplessness to a capability in most activities except self-support. Clearly this means that citizens in different parts of the country with similar conditions are not afforded similar treatment and welfare payment possibilities. The definition used by most states would be similar to the following:

> A medically verifiable permanent major physical or mental impairment, existing singly or in combination, which substantially prevents engaging in a useful occupation within the individual's competence, such as gainful employment or homemaking. A permanent impairment must be expected to continue throughout the person's lifetime. In the absence of significant physical disability, certain personality disorders—including alcoholism or other addictions are excluded.[1]

While that fairly broad definition from California seems to be able to include everybody, and indeed California has a fairly liberal set of interpretations, other states are not quite so liberal. Iowa for example reports the following definition:

> permanent and total impairment of such severity that such disabled person requires assistance from another person performing the normal activities of daily living.

New Hampshire only allows benefits to persons with physical disabilities of a severe nature.

Thus we find for the three major groups of the developmentally disabled, mentally retarded, epileptic and cerebral palsied, state program benefits vary with respect to diagnosis, severity, and income eligibility. And for some states, the formal definition—which may be identical to other states—may be interpreted narrowly or broadly.

Among the activities which the state DD councils should be pursuing is that of securing explicit eligibility for persons with developmental disabilities. Maine, for example, explicitly names retardation as a qualifying diagnosis. Getting APTD eligibility should not only be seen in terms of cash payments to help support the developmentally disabled individual. Maintenance payments are not particularly high; but there are many special needs and special kinds of provisions which can be purchased through the cash grant, quite independent of the levels provided for food and rent, if the state policies will permit. Payment for certain services such as home health aids, prostheses, and an assortment of other items such as special diets or special housing may be made through the basic cash grant mechanism. Clearly, for the individual with developmental disabilities, major benefits are available but are presently quite unequal throughout the nation.

What little information we have about the distribution of payments to persons with different diagnoses is extremely limited. It is primarily based on two surveys made of the Aid to the Permanently and Totally Disabled populations—one in 1962 and another in 1970.[2] In the latter survey, various diagnostic categories were given. A primary diagnosis of 'mental retardation' was present in about 16 percent of the clients on APTD in 1970, 2.5 percent had a primary diagnosis of epilepsy, and 1.8 percent had a primary diagnosis of cerebral, spastic or infantile paralysis. It is not quite known just what the various jurisdictions mean by "retardation." If we were to assume that the percentage of program benefits which went at least to the developmentally disabled was equal to their proportion in the population, in the fiscal year ending June 30, 1972, about $284 million would have been spent on Developmentally Disabled individuals receiving APTD. This money went to an estimated 223,000 recipients per month on an average.

It should be pointed out that individuals who receive APTD are also eligible for Medicaid benefits (which are discussed in another session of the paper). In addition, most persons receiving APTD would be eligible for food stamps as part of their benefit package.

We do not have a cross tabulation of the services received by persons with a primary diagnoses of mental retardation, epilepsy, and cerebral palsy. However, we can indicate a number of the general service categories which APTD recipients receive. This would, for the benefit of those concerned with influencing state plans, indicate areas in which a state can do something, and council members will want to assure themselves that their state is providing some of these services to the Developmentally Disabled. Among the services included are a host of specific and tangible activities performed on behalf of the recipient by others. These, which are called support services, include such activities as homemaker and chore services, home-delivered meals, day care for the recipient, foster care for the recipient, volunteer visiting services including telephones and social outlet types of activities including social centers. Among other services which can be provided are counseling-related activities with respect to getting individuals into or out of certain kinds of medical and nonmedical institutions; including nursing homes, hospitals, and the like. Of course psychiatric and counseling activities should be provided. Dentists', physicians', and prosthetic services (including special appliances) can be and are being made available in various state programs. There are a number of other activities more specifically related to functioning with respect to either the labor market or individual mobility–including referral for vocational rehabilitation, housing improvement and assistance, family planning, employment services, basic or adult education, legal services, and self-care.

AID TO FAMILIES WITH DEPENDENT CHILDREN

Aid to Families with Dependent Children is Title IV of the Social Security Act. This Title has three parts: Part A which constitutes the cash payment and social services authorization, Part B which contains the child welfare provisions, and Part C which represents the Work Incentive Program (WIN). Our discussion will focus primarily on Part A, but we should keep in mind that the HEW Office of Mental Retardation coordination estimates that approximately 44,000 retarded individuals are receiving services through the child welfare provisions. We should also keep in mind that WIN provisions generally exclude incapacitated persons from *mandatory* participation, but there is an authorization which would allow training and related support services (such as health, and child care) to be provided to Developmentally Disabled persons who might qualify for AFDC.

In order for a family to qualify for payments under this program it must have a dependent child. "Dependency" is defined by the death, incapacity or continued absence of at least 1 percent. States may also elect to define a child as dependent if the parents are unemployed and therefore unable to provide support. Within this framework, however, state definitions vary. Some states had, prior to a Supreme Court ruling which prohibited it, a man-in-the-house rule in which a child was not deprived of care and support if there was a man present, regardless of his legal requirements for support of the child or the mother. In some states "continued absence" is defined as over 90 days. In some states all a woman has to do to demonstrate continued absence is to file for divorce or legal separation. Some states encourage reporting of illegitimacy by defining illegitimate children as automatically "deprived of care and support."

In order for a developmentally disabled person to be eligible under AFDC (and recall that he is not eligible because of his disability but irrespective of it) he would have to be an adult with a child, or he would have to be a child who is deprived of care and support of at least one parent. If the primary client happens to be a developmentally disabled adult, usually a mother, then this woman with her child must apply at a local welfare department. If the cause of the child's deprivation is desertion by the father, or if the father of the child was never married to the mother, she must agree to report the child's father to the district attorney and swear out a warrant for nonsupport. She must be domiciled in the state although there are no residence requirements since such requirements were outlawed by the Supreme Court. Her real and personal property and income must be within the described limits. Most states will allow payments for children up to the age of 21 if they are in school. Nine states, in 1969, would pay for children to a maximum age of 18.

Personal property requirements for a family vary: a value of under $500 in 12 states, $500-$1,000 in 22 states, and over $1,000 in 11 states. Only 11 states require liens, recovery, or other assignments.

Figures for the AFDC program are not generally reported by the HEW Office of Mental Retardation coordination. Some estimates indicate that there may be approximately 415,000 children in AFDC families who are Developmentally Disabled. Since the bases for making such estimates are extremely tenuous, it is not clear how much we should rely on those figures. Children or adults in these families are, of course, eligible for cash benefits, along with certain special need provisions, Medicaid benefits, and food stamps.

As is the case in the adult programs, certain individuals not receiving cash grants may be eligible for social services. Persons defined as former or potential recipients can receive social services in various states.

The AFDC social service requirements have been more stringent on the states than have those for the adult programs. While the programs for the aged, blind and disabled did not mandate social services, the program in AFDC did. The states had to agree to have a certain minimum of federally specified services or they would not get reimbursement for assistance payments. Most states therefore have social services programs, most of which extend beyond the minimum.

Among the weakest reporting systems in the federal government, however, are those reporting how social services funds are being expended. In the 1971 survey of the AFDC caseload, a set of codes was established to determine whether services had been provided for a given AFDC case. Thirty services were listed. These services ranged from counseling, guidance and diagnostic services related to employment, and vocational rehabilitation; through such items as pre-school education, day care, improvement of home and financial management, unmarried mothers services, services to establish paternity of children, homemaker services, after-care services following institutional or foster home placement, protective services, and services to the physically and mentally handicapped.

The most recent data on social services comes from a cost analysis conducted in 1971 covering the fiscal year ended June 30, 1973.[3] This was a survey of most of the states participating in the social services programs. In that fiscal year an estimate of $1.6 billion would be spent on social services in Titles IVA, IVB and Title XVI. About 49 percent of the expenditures were made under Title IVA, as compared to 14 percent in the adult titles and 36 percent under the Child Welfare provisions. In Title IVA about 44 percent of the services were for employment and child care and about 24 percent for general family services with another 32 percent called child related services. Although we are going to focus primarily on Title IVA, it should be noted that in Title IVB, 84 percent of the expenditures went to foster care for children and about 6 percent to child care making a total of $538 million. Adoptions made up only 3 percent and other services, including protective services, represented only 7 percent. In Title IVA, homemaker and chore services represented about 5 percent of the total, protective services for children were about 8 percent, employment services associated with WIN were 10 percent, about 14 percent went to foster care and about 29 percent to child care. There were another 13 services covered in the survey which represented approximately 3 percent of the total expenditures which were about $800 million.

In the adult programs about 22 percent of the services expenditures, or about $51 million, went to homemaker and chore services. Twelve percent, or $28 million, went into purchasing institutional living arrangements, 10 percent went to information and referral services, about 9 percent was expended in the remaining 9 services. Of the expenditures on services, Title IVA spent 30 percent on purchased services, the bulk of which was for purchasing child care. A summary table giving approximate amounts and their distribution by program is found in Appendix A. Since the allocation of these programs by state vary widely, State Developmental Disability Councils should look into the kinds of things their own state is prepared to provide.

It is not clear, for instance, whether Developmentally Disabled children in large congregate institutions may, upon their release to some intermediate facility or to some other form of sheltered living arrangement, be eligible for either social services funds or for funds through the intermediate care facilities provisions of Medicaid. Since the Medicaid regulations are not completed at this writing, we do not know what their regulations will allow the states to do.

Developmental Disabilities Councils should look carefully at the way the states are taking advantage of the authority for social service as opposed to

Medicaid services. They both may cover similar populations, especially certain children, and strategies may exist for enhancing the state service program by taking advantage of either the more liberal funding program or the more liberal regulations.

RECENT LEGISLATION

Two pieces of legislation recently passed by the Congress and signed by the President have an impact on the programs that we have just discussed. The State and Local Fiscal Assistance Act of 1972 is generally known as the revenue sharing act. It has a number of sections and provisions, the most important one of which, in this discussion, is the establishment of a ceiling and other restrictions on the provision of social services through the public assistance titles. The second bill recently passed is welfare reform which has in it a federalization of the adult programs.

REVENUE SHARING

Title III of the State and Local Fiscal Assistance Act of 1972 specifically refers to limitation on grants for social services under public assistance programs. The language of that piece is presented in Appendix B. This conference report refers as follows to these provisions:

> Under the substitute, Federal matching for social services under programs of aid to the aged, blind, and disabled and aid to families with dependent children would be subject to a State-by-State dollar limitation, effective beginning with fiscal year 1973. Each State would be limited to its share of $2,500,000,000 based on its proportion of population in the United States. Child care, family planning, services provided to a mentally retarded individual, services related to the treatment of drug addicts and alcoholics, and services provided a child in foster care could be provided to persons formerly on welfare or likely to become dependent on welfare as well as present recipients of welfare. At least 90 percent of expenditures for all other social services, however, would have to be provided to individuals receiving aid to the aged, blind, and disabled or aid to families with dependent children. Until a State reaches the limitation of Federal matching, 75 percent Federal matching would continue to be applicable for social services as under present law.
>
> Under the substitute, services necessary to enable AFDC recipients to participate in the Work Incentive Program would not be subject to the limitation described above; they would continue as under present law, with 90 percent Federal matching and with funding of these services limited to the amounts appropriated. In addition, the conference substitute incorporates the provision of the Senate bill reducing Federal matching for emergency social services from 75 percent to 50 percent.
>
> The conference substitute directs the Secretary of Health, Education, and Welfare to issue regulations prescribing the conditions under which State welfare agencies may purchase

> services they do not themselves provide.
>
> The conferees were told that the Secretary of Health, Education, and Welfare has issued new regulations which require reporting of how social service funds are used. The conferees expect the Secretary to have available detailed information on how social service funds are being spent and on their effectiveness.

Of primary interest to those in the Developmentally Disabled groups was the provision specifically allocating services to individuals by virtue of their being retarded. While this is not targeted to the Developmentally Disabled per se, since it leaves out nonretarded individuals, nonetheless it covers a group of extreme importance. The language of the conference report seems to indicate that "former or potential" recipient requirements are still in effect.

The revenue sharing bill placed a limitation on the amount of service resources which can be spent by the states from federal sources, and it placed certain other limitations on the persons for whom the funds may be expended. The original intent was to place a limitation on each state of 10 percent of its allotment which could be spent on persons not currently receiving a welfare payment. In the course of the deliberations six exceptions were made to those limitations: work-related child-care, family planning, services to mentally retarded children, narcotic addicts, alcoholics and children in foster care. For the populations implied by these exemptions no set percentage limitation is made on the number who can be present, former or potential assistance recipients. This suggests that the amount of a state's social service resources which may be made available may be substantial. State DD councils should take every step to assure that welfare directors exercise the fullest range of this option, keeping in mind that there are many pressures to focus on work-related, child-care, and narcotics addict groups—all of which are very expensive. The fact that, of funds spent on CP's and epileptics, 90 percent must be for those receiving payments requires ingenuity in finding other ways to serve those not on assistance. Since the other provision of H.R. 1 will bring many into active payment status, the problem may not be as extensive as first believed.

Given the rapid growth in social services expenditures it seems a little strange to some of us to talk about the $2.5 billion appropriation as being a "ceiling." Nonetheless, many of the states who were spending social services money at an accelerating rate apparently will be cut back either absolutely as New York and Illinois, or in terms of planning as in most states. For some of these states it is possible to use revenue sharing money to make up deficiencies. It is not clear that the DD Councils have any specific authorization to interpose their concerns at the state and local level, but, on the other hand, there is little to indicate that they need avoid influencing the allocation decisions for expenditure of the revenue sharing funds.

It should be noted that the social service funds are allocated by population and not by prior effort. There is no provision for re-allocation of unused funds from state to state. Thus, if a state elects not to provide matching funds for its full allotment, the federal budget reflects no outlay for the unused portion. DD Councils should point out to such states that many of their current expenditures for the Developmentally Disabled already qualify for matching if the state plan so allows.

H.R. 1

The final form of the Social Security Amendments of 1972 indicates that by January 1974, the administration of welfare cash benefits to the aged, blind and disabled will be federalized and administered by the Social Security Administration. Among the things that this bill does is eliminate the requirement that a handicapped individual be 18 or older. The intent of this change, when it passed the House over a year ago, was to provide special assistance to handicapped children in poor families. The Congress recognized that the cost of raising a handicapped child was greater than that of a nonhandicapped child. Thus it is possible for the children receiving benefits through AFDC to be transferred to the federal program and to be carried with their own case records. This would seem to indicate that the special requirements of these children for a variety of health and other services will be independent of the family's welfare and income status to some extent. In effect, it gives a child his own case on APTD. This would bring him under the minimum payment provisions and thus total family income will be greater than it would be had the whole family been receiving AFDC. By federalizing the administration of benefits certain state practices will be changed. For example, parental responsibility for adult handicapped children will no longer be required as it is in many states. There would be a standard definition of disability virtually identical to that in the Social Security Title II program for the disabled which would read as follows:

> Section. 1614(a)(3): An individual shall be considered to be disabled for purposes of this title if he is unable to engage in any substantial gainful activity by reason of any medically determinable physical or mental impairment which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than 12 months (or, in the case of a child under the age of 18, if he suffers from any medically determinable physical or mental impairment of comparable severity).

Under this definition, most developmentally disabled individuals who meet the income tests should be eligible for a benefit. They most certainly would meet the criteria for "former or potential" recipients and thus qualify for the social services, as well, authorized in the new Title VI.

The determination of disability, as is the case now in the Title II program, would be made by disability determination units which in most states are located in vocational rehabilitation agencies.

It is not clear, however, just what it is that the various other provisions may indicate. A referral to vocational rehabilitation for individuals receiving payments under these programs who are blind or disabled is required (see attachment). It is possible through this language to have the rehabilitation program acting as a broker to assure that handicapped poor children get the services they need. The vocational rehabilitation agency will have access to full 100 percent federal funding for services to the individuals who are referred and accepted for services. While there are many lobbies who have complained that the Rehabilitation people should not be the ones involved in services to children, the alternatives are even more limited. Unless a whole new way of doing business is established in the Social Security Administration, there is no other single program agency or element which can assure long-term follow-up and brokerage on the behalf of these handicapped children from birth on and is backed by access to full federal funds.

The version of the V.R. Act vetoes by the President had major provisions for nonvocational services to the severely disabled. Since the H.R. 1 provisions call for persons who require "services under the State plan for vocational rehabilitation services approved under the Vocational Rehabilitation Act," it seems important that a V.R. Act be passed with a broad authority for services, and that state plans utilize that authority and the authority in H.R. 1 to the fullest.

There are many administrative, regulatory, and policy questions to be raised yet as to exactly how this bill will work. As the program becomes clearer through planning, and as more information on the policy options becomes available, more will be known about what may be possible for the Developmentally Disabled. In the meantime the National Council as well as the State Councils should be vigilant to assure that the developmentally disabled get their fair share of program benefits.

WORKSHOP DISCUSSION

The following summary attempts to capture the gist of discussions during the three sessions on this topic. Many good points were made which could be profitable if presented verbatim, but this approach would prove unweilding. I have, therefore, tried to summarize the salient points and hope that the participants will not feel slighted if their important observations are not fully reflected. Because the discussions of the three sessions covered several similar points, many of these were incorporated into the final draft of the paper and will not be repeated here.

Basically the sessions were devoted to "how to" kinds of questions and we tried to avoid the philosophic as well as questions concerning the role and function of the State Councils. The main thrust of the early discussion was that there is great variance among the state plan programs which an active, aggressive and knowledgeable council might exploit in its own state if it knew what was possible. In general, the audience was reasonably sophisticated in their knowledge of the various programs, but there were still several areas of confusion and ambiguity. For example, some participants did not understand that the payments provisions and the service provisions could, in effect, be viewed separately. They were unsure what the distinctions were, between those persons being eligible for a payment and then also eligible for services, and those persons not getting a payment but, still eligible for services by being a former and potential recipient of payments. One HEW resource person pointed out that under present rules, the person need not be an active payment recipient to get services if he appears to have some of the same qualifying traits as one who is eligible for one of the welfare categories, and if it appears that he might be eligible within 5 years. Such a person can be defined as a potential recipient and be eligible for social services.

There are some subtle discussions of what is possible under social services as distinguished from the payments and special needs provisions. One example mentioned was the payment for transportation. In some cases a state can allow this in its payment provisions as a cost of employment or special need, and in other instances the federal rules allow it as a social service. When transportation is used as a social service, say to rent school buses from the local school system to transport welfare recipients for various purposes, the amount can be included as a social service at the 75 percent match, including the cost of liability insurance. A list of the types of activities which may be considered social services is included in Appendix B.

There was much discussion of the use of residential settings and what is possible with various funding sources. The resource person from Florida pointed out that they had approval for use of social service funds inside an institution (a normally unallowed provision) when there is a discrete program serving an identifiable group in preparation for placement in a community setting. When the program is a unique one, such as one which might be labeled homeward bound, not only could the normal social services be matched (such as caseworker salaries and the like), but in addition, room and board, could be covered for a specified period. When the individual is discharged to the community setting he is also qualified for six months of social service eligibility during his adjustment period. With the advent of some federal funds in areas which were at one time solely state funded, the state funds could be reallocated to specific areas unmatched by federal resources. It was also pointed out that when an individual is eligible, income maintenance funds may be used for maintenance in a community based sheltered environment while the social service funds can be used for the supporting services.

In further discussion of the persons who might be eligible for social services but who are not eligible for payments, numerous questions were raised about the income tests which might be in effect. These income tests are usually made up between the State and the SRS regional office. They usually far exceed the income tests for eligibility for welfare payments. For example, in Florida a family of four could have annual income up to $8,700 and still meet the income test for eligibility for social services. The Florida Division of Retardation found that about 93 percent of the families it served could meet the income test for social services. It was pointed out that it is in the interest of the state to have a liberal income test for social services so that the maximum number of individuals who are getting services could be covered by federal funds.

Many questions were raised about the impact of the new Title XVI federalized program of income maintenance. Questions were raised with respect to how this program would integrate with social services, residual state supplemental programs and the AFDC program. Unfortunately the answers to most of the questions were not available and will not be until the planners in the Social Security Administration, headed by Sumner Whittier, former Executive Director of the National Society for Crippled Children and Adults decide on their positions. For example, when welfare reform planning was first begun, the assumption was that there would be a federalized family program with a national standard. Then all seriously disabled children in families with incomes below the national standard would be eligible for Title XVI. Now, however, it is unclear just which standards may apply. We do not know if they will apply to children in families with the father present and working full time, but at low wages. The standards could be the state standards, but this would mean a child in one state might be eligible and another in the same condition in a different state may not. A federal standard which would cover the highest standard states might include many families in low standard states who would not otherwise be eligible.

In the same manner, we do not know what the income standards might be for social services–will they continue to be worked out between states and SRS regional offices or will Social Security determine these standards. We do not know yet if states with income maintenance programs to supplement the federal program will be allowed liens on their portion of the program while liens will not be allowed on the Federal portion. In most instances the council members were admonished to have their states or their congressional delegations advance recommendations which might result in regulations serving the best interests of their target groups.

There was also a good deal of discussion regarding the impact of the ceiling on the social services established by the Revenue Sharing bill and the various colloquies on the definition of who the mentally retarded are who are to be exempted from the limitation that 90 percent must be active recipients of welfare payments.

During the floor debate on acceptance of the House-Senate Conference Report on H.R. 14370, questions were raised in both houses concerning the interpretation of the term "mentally retarded" under Title III of the bill. In this section of the legislation, states are permitted to continue to receive 75 percent federal reimbursement on behalf of present, past and potential welfare recipients in six specified service categories, including aid to mentally retarded children and adults. The question raised by Congressman Hall in the House and Senator Dole in the Senate was: "Would the term 'mentally retarded' be interpreted to include all developmentally disabled persons – including non-retarded cerebral palsied and epileptic individuals?"

They received sharply divergent answers. In responding to Hall's query, Congressman Wilbur Mills, Chairman of the House Ways and Means Committee, commented, "There certainly would be no question as to providing these services under the exception to individuals who have the same types of difficulties in their functioning which generally characterize mentally retarded children and adults."

When faced with a similar question, however, Senator Russell Long, Chairman of the Senate Finance Committee, responded quite differently. He noted, "If a 'developmentally disabled' person is mentally retarded, then Federal matching is available whether or not the person is on welfare. If 'developmentally disabled' persons are not mentally retarded, then they fit in the category in which 90 percent of the funds must go to welfare recipients."

Since there is a clear difference of opinion between the two houses of Congress, resolution of the issue will rest with regulation writers in HEW.

It was important to point out in the discussion that this does not mean that CP and E's who are not retarded (perhaps only 40 percent are not as one member of the audience observed) are not served. Many will be active recipients and therefore eligible. Of those not active recipients and not retarded, up to 10 percent may be served. Given the national definition of disability in the Title XVI program, it seems unlikely that very many such individuals will not be eligible if they are poor regardless of how the federal service regulations come out.

There were many other points great and small. One HEW official pointed out that the welfare reform bill also eliminated the requirement for statewideness in social services. This would allow local councils who can put together a service package to get it approved even though other parts of the state do not have a similar package. Previously a service program could only be approved if it were available in all parts of a state.

It was pointed out that the DD Act would be up for hearings in early 1973, so that state councils should be preparing their positions for improvements in the legislation that would assist them in their work.

It was pointed out that increasingly the Nixon Administration would be moving away from categorical programs and earmarked funding. The effect of this would be to shift decision making on priorities to the states where a strong DD council may do very well or very poorly, but responsibility for the decisions would rest with the state.

And perhaps the most vital point to be made was that there are no magic formulas for how to get the councils to be effective for their constituencies. Hard work, hustle, and being knowledgeable about the in's and out's and the angles would be the key. The ability to exploit the provisions discussed here would come from no simple federal regulation. Most of the possibilities in the provisions discussed here lie with the states and therefore the share falling to the developmentally disabled will depend on how well that constituency fares relative to other groups in a state. It is a challenging prospect.

Appendix A

ESTIMATED NATIONAL RESULTS
SOCIAL SERVICE EXPENDITURE DETAIL BY CATEGORY

Fiscal Year 1971

(thousands of dollars)

	Total		*Expenditure Amounts*				*Percent of Total*				*Percentage Distributions*			
Social Service	*Amount*	*% of Total*	*Adult*	*IVA*	*IVB*	*Other*	*Adult*	*IVA*	*IVB*	*Other*	*Adult*	*IVA*	*IVB*	*Other*
All Services	$1,642,049	100.0%	$229,157	$799,064	$596,812	$17,016	100.0%	100.0%	100.0%	100.0%	14.0%	48.7%	36.3%	1.0%
Information & Referral	65,975	4.0	24,458	36,403	4,220	894	10.7	4.6	0.7	5.3	37.1	55.1	6.4	1.4
Adoption	53,719	3.3	–	35,814	17,905	–	–	4.5	3.0	–	–	66.7	33.3	–
Child Foster Care	613,489	37.5	–	111,878	501,587	24	–	14.0	84.0	0.1	–	18.2	81.8	–
Unmarried Mothers	24,650	1.5	–	19,292	5,244	114	–	2.4	0.9	0.7	–	78.2	21.3	0.5
Child Protection	81,970	5.0	–	67,390	14,580	–	–	8.4	2.4	–	–	82.2	17.8	–
Child Care	269,619	16.4	–	233,410	35,800	409	–	29.2	6.0	2.4	–	86.5	13.3	0.2
Child Development	28,966	1.8	–	24,106	4,860	–	–	3.0	0.8	–	–	83.2	16.8	–
Adult & Family Functioning	32,256	2.0	8,953	16,538	3,068	3,697	3.9	2.1	0.5	21.7	27.7	51.3	9.5	11.5
Family Planning	6,819	0.4	582	6,206	–	31	0.3	0.8	–	0.2	8.5	91.0	–	0.5
Money Management	13,693	0.8	2,843	10,395	–	455	1.2	1.3	–	2.7	20.8	75.9	–	3.3
Housing	31,802	1.9	8,743	21,409	128	1,522	3.8	2.7	–	8.9	27.5	67.3	0.4	4.8
Homemaker & Chore	97,157	5.9	50,681	40,757	2,698	3,021	22.1	5.1	0.5	17.8	52.2	41.9	2.8	3.1
WIN Employment	80,017	4.9	–	80,017	–	–	–	10.0	–	–	–	100.0	–	–
Employment & Training	54,654	3.3	17,150	36,373	256	875	7.5	4.6	0.1	5.1	31.4	66.5	0.5	1.6
Health	41,796	2.5	19,970	20,366	512	948	8.7	2.5	0.1	5.6	47.8	48.7	1.2	2.3
Alco. & Drug Treatment	7,496	1.1	12,954	3,207	–	1,335	5.6	0.4	–	7.8	74.1	18.3	–	7.6
Adult Protection	21,311	1.3	19,680	–	–	1,631	8.6	–	–	9.6	92.3	–	–	7.7
Home & Comm. Living	16,697	1.0	16,448	–	–	249	7.2	–	–	1.5	98.5	–	–	1.5
Institutional Living	28,628	1.7	27,654	–	–	974	12.1	–	–	5.7	96.6	–	–	3.4
Special Needs	13,840	0.8	4,539	8,769	128	404	2.0	1.1	–	2.4	32.8	63.4	0.9	2.9
Other Services	47,495	2.9	14,502	26,734	5,826	433	6.3	3.3	1.0	2.5	30.5	56.3	12.3	0.9

Appendix E

TITLE III – LIMITATION ON GRANTS FOR SOCIAL SERVICES UNDER PUBLIC ASSISTANCE PROGRAMS

SEC. 301. (a) Title IX of the Social Security Act is amended by adding at the end thereof the following new section:

"LIMITATION ON FUNDS FOR CERTAIN SOCIAL SERVICES

"SEC. 1130. (a) Notwithstanding the provisions of section 3(a) (4) and (5), 403(a)(3), 1003(a) (3) and (4), 1403(a) (3) and (4), or 1603(a) (4) and (5), amounts payable for any fiscal year (commencing with the fiscal year beginning July 1, 1972) under such section (as determined without regard to this section) to any State with respect to expenditures made after June 30, 1972, for services referred to in such section (other than the services provided pursuant to section 402(a)(19)(G)), shall be reduced by such amounts as may be necessary to assure that–

"(1) the total amount paid to such State (under all of such sections) for such fiscal year for such services does not exceed the allotment of such State (as determined under subsection (b)); and

"(2) of the amounts paid (under all of such sections) to such State for such fiscal year with respect to such expenditures, other than expenditures for–

"(A) services provided to meet the needs of a child for personal care, protection, and supervision, but only in the (i) in order to enable a member of such child's family to accept or continue in employment or to participate in training to prepare such member for employment, or (ii) because of the death, continued absence from the home or incapacity of the child's mother and the inability of any member of such child's family to provide adequate care and supervision for such child;

"(B) family planning services;

"(C) services provided to a mentally retarded individual (whether a child or an adult), but only if such services are needed (as determined in accordance with criteria prescribed by the Secretary) by such individual by reason of his condition of being mentally retarded;

"(D) services provided to an individual who is a drug addict or an alcoholic, but only if such services are needed (as determined in accordance with criteria prescribed by the Secretary) by such individual as part of a program of active treatment of his condition as a drug addict or an alcoholic; and

"(E) services provided to a child who is under foster care in a foster family home (as defined in section 408) or in a child-care institution (as defined in such section), or while awaiting placement in such a home or institution, but only if such services are needed (as determined in accordance with criteria prescribed by the Secretary) by such child because he is under foster care,

not more than 10 per centum thereof are paid with respect to expenditures incurred in providing services to individuals who are not recipients of aid or assistance (under State plans approved under titles I, X, XIV, XVI, or part A of title IV), or applicants (as defined under regulations of the Secretary) for such aid or assistance.

"(b)(1) For each fiscal year (commencing with the fiscal year beginning July 1, 1972) the Secretary shall allot to each State an amount which bears the same ratio to $2,500,000,000 as the population of such State bears to the population of all the States.

"(2) The allotment for each State shall be promulgated for each fiscal year by the Secretary between July 1 and August 31 of the calendar year immediately preceding such fiscal year on the basis of the population of each State and of all of the States as determined from the most recent satisfactory data available from the Department of Commerce at such time; except that the allotment for each State for the fiscal year beginning July 1, 1972, and the following fiscal year shall be promulgated at the earliest practicable date after the enactment of this section but not later than January 1, 1973.

"(c) For purposes of this section, the term 'State' means any one of the fifty States or the District of Columbia."

(b) Sections 3(a)(4)(E), 403(a)(3)(D), 1003(a)(3)(E), 1403(a)(3)(E), and 1603(a)(4)(E) of such Act are amended by striking out "subject to limitations' and inserting in lieu thereof "under conditions which shall be."

(c) Section 403(a)(5) of such Act is amended to read as follows:

"(5) in the case of any State, an amount equal to 50 per centum of the total amount expended under the State plan during such quarter as emergency assistance to needy families with children."

(d) Sections 3(a), 403(a), 1003(a), 1403(a), and 1603(a), of such Act are amended, in the matter preceding paragraph (1) of each such section, by striking out "shall pay' and inserting in lieu thereof "shall (subject to section 1130) pay."

(e) The amendments made by this section (other than by subsection (b)) shall be effective July 1, 1972, and the amendments made by subsection (b) shall be effective January 1, 1973.

Appendix C

REVENUE SHARING AND THE 50 BIGGEST CITIES

The table below shows the amount of revenue sharing money that will flow into each of the nation's 50 largest cities in fiscal 1973, and matches the amount against demographic and economic characteristics of those cities. The cities are ranked in order according to their population size.

The wide disparity among cities in revenue sharing dollars per capita results from the way that money is distributed at the intra-state level. Congress deliberately established a mechanism that would yield uneven sums, said Sen. Russell B. Long, D-La., chairman of the Senate Finance Committee and the architect of the intra-state distribution formula. For a city to do unusually well, like New York City ($31.34 per capita), it must score highly on all the factors in the intra-state distribution formula, which means it must be big, have a high-tax effort and a relatively large percentage of poor. Conversely, the cities that do poorly like San Diego, Calif. ($9.36 per capita), Jacksonville, Fla. ($7.51 per capita), and Rochester, N.Y. ($7.74 per capita) score relatively low on the factors that measure tax effort and percentage of poor.

	Amount of revenue sharing	Revenue sharing as percent of city expenditures	Population	Non-white population percent	Percent population under poverty level $4,113 family income)	Revenue sharing dollars per capita
New York	247,524,126	3.1	7,895,563	23.4	11.5	$31.34
Chicago	69,477,799	9.1	3,369,359	34.4	10.6	20.62
Los Angeles	35,442,819	5.9	2,809,596	22.8	9.9	12.61
Philadelphia	43,758,115	6.3	1,950,098	34.4	11.2	22.44
Detroit	36,530,556	8.5	1,512,893	44.5	11.3	24.15
Houston	14,029,925	9.3	1,232,802	26.6	10.7	11.38
Baltimore	23,881,944	3.6	905,759	47.0	14.0	26.37
Dallas	9,699,255	5.9	844,401	25.8	10.1	11.49
Washington, D.C.	23,647,564	2.7	756,510	72.3	12.7	31.26
Cleveland	14,107,681	7.9	750,879	39.0	13.4	18.79
Indianapolis	6,983,136	5.5	745,739	18.4	7.1	9.36
Milwaukee	11,221,768	7.2	717,372	15.6	8.1	15.64
San Francisco	19,276,751	3.9	715,674	28.6	9.9	26.94
San Diego	6,527,384	5.7	697,027	11.1	9.3	9.36
San Antonio	7,785,895	12.2	654,153	8.6	16.1	11.90
Boston	17,753,054	4.1	641,071	18.2	11.7	27.69
Memphis	9,826,564	4.3	623,530	39.2	15.7	15.76
St. Louis	12,702,004	7.9	622,236	41.3	14.3	20.41
New Orleans	14,744,411	12.7	593,471	45.5	21.6	24.84
Phoenix	9,280,443	10.2	581,562	6.7	8.8	15.96
Columbus	5,697,361	5.5	540,025	19.0	9.8	10.55
Seattle	9.863,462	7.4	530,831	12.6	6.0	18.58

Jacksonville	3,972,067	4.4	528,865	22.9	14.1	7.51
Pittsburgh	11,679,788	12.0	520,117	20.7	11.1	22.46
Denver	12,189,871	6.9	514,678	11.0	9.4	23.68
Kansas City, Mo.	10,222,093	7.8	507,330	22.8	8.9	20.15
Atlanta	4,583,171	2.8	497,421	51.6	15.9	9.21
Buffalo	7,328,071	3.4	462,768	21.3	11.2	15.84
Cincinnati	8,501,849	3.4	452,524	28.1	12.8	18.79
Nashville-Davidson	6,378,838	3.8	477,877	19.9	10.4	14.24
San Jose, Calif.	4,033,206	5.0	445,779	6.4	6.4	9.05
Minneapolis	4,814,471	5.2	434,400	6.4	7.2	11.08
Fort Worth	4,207,340	7.7	393,476	20.6	10.3	10.69
Toledo	4,467,549	6.5	383,818	14.3	7.7	11.64
Newark	8,437,328	4.1	381,930	56.0	18.4	22.09
Portland	8,579,738	13.4	380,620	7.8	8.1	22.54
Oklahoma City	6,783,125	11.2	386,856	16.0	10.6	18.39
Louisville	9,480,686	14.9	361,958	24.1	13.0	26.19
Oakland	5,775,003	6.1	361,561	40.9	12.2	15.97
Long Beach	3,746,725	3.3	358,633	8.2	8.2	10.45
Omaha	3,640,464	7.5	346,929	10.6	7.2	10.49
Miami	6,959,236	13.4	334,859	23.4	16.4	20.78
Tulsa	3,013,250	5.9	330,350	13.4	9.0	9.12
Honolulu	12,542,903	8.4	324,871	66.1	6.9	38.61
El Paso	5,473,903	17.2	322,261	33.0	16.8	16.99
St. Paul	4,450,117	5.4	309,828	4.6	6.4	14.36
Norfolk	6,740,023	4.3	307,951	30.2	16.1	21.89
Birmingham	7,099,587	16.3	300,910	42.2	17.4	23.59
Rochester	2,293,973	1.4	296,233	17.6	8.9	7.74
Tampa	5,640,879	14.5	277,767	20.0	14.9	20.31

SOURCE: Joint Committee on Internal Revenue Taxation; Census Bureau.

Appendix D

SOCIAL SERVICES AND THE STATES

Rushing to take advantage of the 3-1 matching grants available under the open-ended social services program, state governments in August submitted spending estimates that would have required the federal government to put up $4.7 billion in matching funds. But in the revenue sharing-social services bill, Congress clamped a lid of $2.5 billion a year on social services, and required that the money be distributed under a population formula. The program cost $1.7 billion in fiscal 1972. As a result of the congressional action, 23 states and the District of Columbia will have to cut back on their social services spending plans. Nonetheless, the increase of roughly $800 million in social services money from fiscal 1972 to fiscal 1973 will enable nearly every state to increase its federal services grant over last year's level.

	Fiscal 1972 federal share for social services	Disbursement of $2.5 billion on basis of population	August estimates of U.S. share of fiscal 1973 social service costs	Difference: Fiscal 1973 estimates, allotment ceiling
Ala.	$ 12.5	$ 42.2	$ 135.0	$− 92.8
Alaska	7.6	3.8	19.0	− 15.2
Ariz.	4.3	22.2	6.3	+ 15.9
Ark.	9.2	23.5	8.8	+ 14.8
Calif.	221.0	245.2	273.0	− 27.7
Colo.	18.5	27.5	30.6	− 3.1
Conn.	9.6	37.2	22.7	+ 14.5
Del.	15.2	6.8	26.4	− 19.6
D. of C.	9.2	9.0	20.8	− 11.8
Fla.	65.9	85.2	113.6	− 28.3
Ga.	32.8	56.5	206.5	− 150.0
Guam	.2	—	.2	—
Hawaii	1.2	9.5	2.6	+ 6.9
Idaho	1.5	8.8	24.9	− 16.1
Ill.	181.3	135.8	211.6	− 75.9
Ind.	6.3	64.0	20.0	+ 44.0
Iowa	10.0	34.5	13.5	+ 21.0
Kan.	6.4	27.5	7.4	+ 20.1
Ky.	12.4	39.8	30.0	+ 9.7
La.	29.5	44.8	34.9	+ 9.9
Maine	6.3	12.2	6.7	+ 5.6
Md.	19.5	48.5	415.7	− 367.2
Mass.	51.8	69.8	96.0	− 26.2
Mich.	31.6	109.0	108.9	+ .1
Minn.	39.0	47.0	72.4	− 25.4
Miss.	1.7	27.0	269.4	− 242.4
Mo.	13.1	57.5	16.9	+ 40.6
Mont.	2.9	8.5	3.3	+ 5.2
Neb.	7.2	18.2	12.6	+ 5.7
Nev.	1.6	6.2	2.0	+ 4.6
N.H.	2.7	9.2	4.9	+ 4.4
N.J.	30.9	88.5	415.9	− 327.7
N.M.	11.5	12.5	33.4	− 20.9
N.Y.	497.7	223.0	854.9	− 631.9
N.C.	19.9	62.5	50.9	+ 11.6
N.D.	3.3	7.5	4.0	+ 3.5
Ohio	18.3	130.5	90.0	+ 40.5
Okla.	25.4	31.5	48.5	− 17.0
Ore.	24.6	26.2	25.2	+ 1.1
Pa.	54.9	144.0	106.5	+ 37.5
P.R.	3.0	—	4.0	—
R.I.	5.2	11.8	15.8	− 4.1
S.C.	[illegible].3	31.8	176.2	− 144.5
S.D.	2.2	8.2	2.9	+ 5.3
Tenn.	17.6	48.5	227.6	− 179.1
Tex.	58.0	139.0	179.5	− 40.5
Utah	4.3	13.2	5.2	+ 8.0
Vt.	2.3	5.5	2.6	+ 2.9
V.I.	.3	—	.2	—
Va.	16.2	57.2	32.1	+ 25.1
Wash.	31.8	41.8	90.6	− 48.8
W.Va.	7.4	21.2	16.8	+ 4.5
Wis.	36.5	54.2	58.5	− 4.2
Wyo.	.5	4.2	.6	+ 3.6
Total	$1,710.2	$2,500.0	$4,658.2	$−2,520.4 $+ 366.7

SOURCE: HEW Department

Appendix E

"REHABILITATION SERVICES FOR BLIND AND DISABLED INDIVIDUALS

"SEC. 1615. (a) In the case of any blind or disabled individual who—

"(1) has not attained age 65, and

"(2) is receiving benefits (or with respect to whom benefits are paid) under this title.

the Secretary shall make provision for referral of such individual to the appropriate State agency administering the State plan for vocational rehabilitation services approved under the Vocational Rehabilitation Act, and (except in such cases as he may determine) for a review not less often than quarterly of such individual's blindness or disability and his need for and utilization of the rehabilitation services made available to him under such plan.

"(b) Every individual with respect to whom the Secretary is required to make provision for referral under subsection (a) shall accept such rehabilitation services as are made available to him under the State plan for vocational rehabilitation services approved under the Vocational Rehabilitation Act; and the Secretary is authorized to pay to the State agency administering or supervising the administration of such State plan the costs incurred in the provision of such services to individuals so referred.

"(c) No individual shall be an eligible individual or eligible spouse for purposes of this title if he refuses without good cause to accept vocational rehabilitation services for which he is referred under subsection (a).

Appendix F

REVENUE SHARING AND THE STATES

The table below shows the amount of revenue sharing money that will flow into each state in fiscal 1973, and matches the amount against demographic and economic characteristics of the states. The amount listed for each state is the entire revenue sharing sum that will be distributed within the state's borders–for local governments as well as for the state-government. In each case, the state government will get one-third of the total amount, and two-thirds will be divided among lower jurisdictions. While all the states benefit under the legislation, some benefit more than others. The winners are those who peculiar demographic characteristics score highly under either of the two formulas used for disbursing revenue sharing money. These include big urbanized states with high-tax efforts and large concentrations of poor, such as California and New York, and rural states in the South which also have large concentrations of poor. The losers are states like Connecticut, Illinois, Ohio and Pennsylvania, which fall between the extremes.

	Amount of revenue sharing	Percent of total revenue sharing	State population	Percent of U.S. population	State government share as percent of state expenditure	Revenue sharing dollars per capita
Ala.	$116,100,000	2.2	3,444,165	1.7	3.4	$33.70
Alaska	6,300,000	0.1	300,382	0.1	0.5	20.97
Ariz.	50,200,000	0.9	1,770,900	0.9	3.0	28.35
Ark.	55,000,000	1.0	1,923,295	0.9	3.7	28.59
Calif.	556,100,000	10.5	19,953,134	9.8	2.6	27.87
Colo.	54,600,000	1.0	2,207,259	1.1	2.5	24.73
Conn.	66,200,000	1.2	3,031,709	1.5	1.6	21.84
Del.	15,800,000	0.3	548,104	0.3	1.8	28.59
D.C.	23,600,000	0.4	756,510	0.4	2.7	31.26
Fla.	146,000,000	2.8	6,789,443	3.3	3.0	21.50
Ga.	109,900,000	2.1	4,589,575	2.3	2.8	23.94
Hawaii	23,800,000	0.4	768,561	0.4	1.1	30.96
Idaho	19,900,000	0.4	712,567	0.4	2.4	27 92
Ill.	274,700,000	5.2	11,113,976	5.5	2.7	24.71
Ind.	104,300,000	2.0	5,193,669	2.6	2.8	20.08
Iowa	77,000,000	1.5	2,824,376	1.4	3.0	27.26
Kan.	52,800,000	1.0	2,246,578	1.1	3.2	23.50
Ky.	87,300,000	1.6	3,218,706	1.6	2.5	27.12
La.	113,600,000	2.1	3,641,306	1.8	2.9	31.19
Maine	31,100,000	0.6	992,048	0.5	2.4	31.34
Md.	107,000,000	2.0	3,922,399	1.9	3.0	27.27
Mass.	163,000,000	3.1	5,689,170	2.8	2.3	28.65

Mich.	221,900,000	4.2	8,875,083	4.4	2.4	25.00
Minn.	103,900,000	2.0	3,804,971	1.9	3.3	27.30
Miss.	90,700,000	1.7	2,216,912	1.1	4.3	40.91
Mo.	98,800,000	1.9	4,676,501	2.3	2.6	21.12
Mont.	20,600,000	0.4	694,409	0.3	2.0	29.66
Neb.	42,900,000	0.8	1,483,493	0.7	4.0	28.91
Nev.	11,100,000	0.2	488,738	0.2	1.8	22.71
N.H.	15,200,000	0.3	737,681	0.4	1.7	20.60
N.J.	163,600,000	3.1	7,168,164	3.5	2.5	22.82
N.M.	33,200,000	0.6	1,016,000	0.5	2.8	32.67
N.Y.	591,400,000	11.2	18,236,967	9.0	3.6	32.42
N.C.	135,500,000	2.6	5,082,059	2.5	3.6	26.66
N.D.	19,700,000	0.4	617,761	0.3	2.6	31.88
Ohio	207,000,000	3.9	10,652,017	5.2	2.4	19.43
Okla.	59,400,000	1.1	2,559,229	1.3	2.2	23.21
Ore.	56,200,000	1.1	2,091,385	1.0	2.1	26.87
Pa.	274,000,000	5.2	11,793,909	5.8	2.0	23.23
R.I.	23,600,000	0.4	946,725	0.5	1.8	24.92
S.C.	81,500,000	1.5	2,590,516	1.3	4.0	31.46
S.D.	25,100,000	0.5	665,507	0.3	3.4	37.71
Tenn.	98,400,000	1.9	3,923,687	1.9	3.1	25.07
Tex.	244,500,000	4.6	11,196,730	5.5	2.9	21.83
Utah	31,400,000	0.6	1,059,273	0.5	2.3	29.64
Vt.	14,800,000	0.3	444,330	0.2	1.7	33.30
Va.	105,200,000	2.0	4,648,494	2.3	2.6	22.63
Wash.	84,100,000	1.6	3,409,169	1.7	1.5	24.66
W. Va.	52,300,000	.9	1,744,237	0.9	2.2	29.98
Wis.	133,900,000	2.5	4,417,731	2.2	3.5	30.30
Wyo.	9,700,000	0.2	332,416	0.2	1.8	29.18

1. 1970 Census
2. Based on expenditures by states in 1971

SOURCE: Joint Committee on Internal Revenue Taxation; Census Bureau

Services Available to the Developmentally Disabled Through Section 314 (d) of The Partnership for Health Act.

Ellen Z. Fifer

The programs of Comprehensive Health Planning and Developmental Disabilities, both established by federal law, present numerous opportunities for cooperative efforts and mutual benefits which we should explore in some depth, beyond the title of the workshop, which only addresses what the 314(d) funding mechanism may be expected to provide. We mean "benefits" in the sense of good program management, efficient resource allocation and effective programs for the developmentally disabled. Cooperative ventures, if ever permitted to develop, can strengthen and enhance individual endeavors.

AN OVERVIEW OF THE PARTNERSHIP FOR HEALTH ACT

The Comprehensive Health Planning Act passed by the federal Congress in 1966 mandates planning comprehensively for health services, manpower and facilities. This is to be accomplished through state agencies, with full-time staff, and the help of Advisory Councils of specified composition. The Councils must consist of more than one-half consumers of health services, the other minority percentage to be broadly representative of health providers, including responsible state and local officials. It is remarkably like the Developmental Disabilities legislation in concept, although the percentages and representatives are, of course, different.

The Act, known as the Partnership for Health Act, further directs that regional planning capability be developed within the state, referred to as Areawide Comprehensive Health Planning Agencies. In most states this process is well along, with all or most of the population residing in regions which have such a planning agency. However, Areawide Comprehensive Health Planning Agencies may be in early stages of development or not yet under way in some parts of the country. These planning Councils must also be consumer-dominated and provider representative, must raise between 25-50% of their budgets locally, and can receive federal support for the remainder. In most parts of the country the

Areawide Comprehensive Health Planning Agencies are non-profit corporations with their Councils serving as Boards of Directors. In some states there are regional governmental units–Economic Development Commissions or similar structures, which provide the organizational base for Comprehensive Health Planning.

Another section of the Comprehensive Health Planning–Partnership for Health Act provides for a formula grant to each state health authority, the so-called 314(d) funds with which this workshop is particularly concerned. As in the case of other "formula" grants, the amount is calculated in direct proportion to the population of the state, and in inverse ratio to its average per capita income. In any case, the grant is then provided without restriction as to its use to the State Health Authority, with at least 15% provided for the State Mental Health Authority. These "authorities" may be lodged in the same agency, but in many states are located in different departments of state government. The major stipulation in the use of the 314(d) funds is that 70% must be used for "local services." The interpretation of what comprises "local services" of course has been of considerable interest and a matter of debate in the various states and HEW regions.

The regulations promulgated by HEW to implement the Partnership for Health Act include some significants requirements as follows:

"Policies and procedures must provide methods for: (1) coordinating the state agency's planning activities with specialized health planning and *other related planning activities such as the development of mental retardation plans,* construction plans for health and medical facilities, *community mental health plans,* and State physical and economic planning; (2) considering the most effective and efficient manner of *meeting health needs in the fields of welfare, education and rehabilitation;* (3) *considering the special needs of high-risk population groups for preventive and health care services.*"

The law itself, P.L. 89-749, states that the agency must "*provide for encouraging cooperative efforts* among governmental and nongovernmental agencies, organizations and groups concerned with health services, facilities and manpower, *and for cooperative efforts between such agencies, organizations and groups and similar agencies, organizations and groups in the fields of education, welfare and rehabilitation.*"

So there is a mandate, both in law and in regulation, for those of us in Comprehensive Health Planning to work closely with the service systems which relate to Developmental Disabilities Planning. The Director of Comprehensive Health Planning is designated as a member of the State Developmental Disabilities Advisory Council under P.L. 91-517.

OVERLAPS AND COMMON CONCERNS

Beyond the requirements that federal law imposes on us, what are the real life justifications for a close partnership between Comprehensive Health Planning and Developmental Disabilities Planning?

A Human Services Relationship

One that is dictated by our common concern in helping client populations. For Comprehensive Health Planning it is primarily the mentally and physically ill and disabled, but much of our attention is devoted to "prevention," which applies across the board to all citizens, in efforts to protect people from health hazards, teaching good health practices, and preventing the onset of disease and disability. The World Health Organization has defined health as "not merely the absence of disease and disability but the presence of physical, mental and social well-being." Surely the well-being of the cerebral palsied, epileptic and mentally retarded is part of this universe.

The preventive aspects which have always been the primary concern of Public Health are identical with and inclusive of the primary prevention of Developmental Disabilities. The early evaluation and detection function that must be available and provided for all infants and children must certainly be available in order to identify those with Developmental Disabilities.

A Similar Role

The words that appear in the Developmental Disabilities Act and the Comprehensive Health Planning Act indicate that in our respective areas we should be: coordinators, convenors, planners. Both groups have diverse constituencies with differing professional training, various approaches to helping the client population, and a wide range of concerns, sometimes conflicting. The Developmental Disabilities legislation calls upon the Planning and Advisory Councils and staffs to bring these diverse groups together, seek out their commonalities, "facilitate the development of comprehensive services." The mandate to Comprehensive Health Planning is exactly the same, dealing with its own scope of interest and constituency; to try to develop for all people access to a continuum of health care including prevention, developing a rational system from a non-system, and dealing with multiple interests and diverse populations.

Both laws mandate the development of a comprehensive and continuing plan. In Developmental Disabilities, we must order goals and objectives, identify priorities and make them known so that (a) the many workers and agencies in the communities and states have a better understanding of how their activity fits into an overall framework and (b) new programs are designed to fill gaps, rather than duplicate what already exists. The mandate to Comprehensive Health Planning in its sphere is identical.

Both laws provide for formula grants to the states to work with, to set up the planning and administrative machinery, and to begin to implement some of the plans. Although the financial mechanisms and matching requirements are not identical, they are very similar.

Functional Overlap

Of the nine pre-existing federally funded programs identified in the Developmental Disabilities legislation which the program must "complement, augment and not duplicate," five are of equal concern to Comprehensive Health Planning, and have been closely related to the Comprehensive Health Planning Process since its onset. These are Crippled Children's Services, Medical Assistance, Maternal and Child Health, Mental Health, and of course, Comprehensive Health Planning itself.

Therefore, we are working with the same program elements, at least in part, and must of necessity relate our work programs. If, in identifying the role of the State Crippled Children's Services, both Comprehensive Health Planning and Developmental Disabilities Planning make recommendations without prior consultation and the recommendations are poles apart, what effect will this have on the services provided? How can the Director of Crippled Children's Services respond to such opposing directives or recommendations? It is incumbent on us both to relate our objectives, to resolve conflicts and design programs that will benefit both consumer constituencies if that is possible. If it is not possible, and we must face the fact that resolution of differences in a spirit of sweetness and light is not always possible, then at least we can identify our differences in a rational way, so that the ultimate decision makers in local, state and federal government can exercise their options.

The Medical Assistance Program is both a boon and a threat to the developmentally disabled: a boon because it provides federal resources to match those of state and county to pay for a variety of health services, including certain kinds of residential care. It is a threat in that it is basically a "medical care" payments program and does not take into account the pressing needs of the disabled for the multitude of other services required for a satisfying, productive and meaningful life. In most states the largest portion of state funds expended for health care is in the Medical Assistance category. It is a major responsibility of Comprehensive Health Planning to influence the allocation of resources available for health care, and the use of Medical Assistance funds is a most significant item.

Similarly, Developmental Disabilities will want to exercise its influence on this funding mechanism, so that it does not restrict or dominate the decisions about residential care for the developmentally disabled. We must work cooperatively on this matter. Maternal and Child Health and Crippled Children's funds have been expended for years on programs which seek to prevent maternal disease and injury, to prevent birth defects and birth injuries, and to assist in the early detection and treatment of problems in infancy and childhood. It is a fertile field for the commingling of funds so that in fact we reach an irreducible minimum of such disabilities. The entire spectrum of services concerning Prevention, Early Detection and Diagnosis should be co-planned between those Program Directors responsible for the expenditure of these funds, Developmental Disabilities and Comprehensive Health Planning.

Federal Initiatives

There is considerable interest being shown at the federal level for the integration of human services programs. After funding hundreds of categorical programs over the past twenty years, some categorized by disease or disability, others directed at specified age groups and still other funds distributed according to types of service providers, the latest strategy is to knit us all back together again. This is a horrendous task and is not likely to be achieved by putting everyone in a huge HEW in each state. Nevertheless, many states have taken that approach. A much more fundamental kind of regrouping is probably necessary, and it is my own contention that effective integration must take place at the community level, with full support from the state and federal back-up agencies. A rational delivery system is not impossible, but it will take tremendous administrative clout to achieve. The Allied Services Act proposed in the federal Congress in 1972 provides incentives to take the first steps in this direction. Both Developmental Disabilities and Comprehensive Health Planning can assist in this effort, but most proceed in the same direction at the same time if anything at all is to occur. The state bureaucracies, no less than federal, are large and ponderous, jealous of their prerogatives and not inclined to lose an ounce of authority or a dollar of resources without clear direction from some higher authority.

314(d) FUNDS

The formula grant to states for Public Health and Mental Health, represented in the 314(d) allocation is, to be honest, not a very substantial source of funds. In Minnesota, for example, the entire allocation to the state for Public Health Services under this grant is about 1.3 million dollars. Many states with larger populations and/or lower per capita income receive much more. Although not an inconsiderable sum, the demands for it are immense, including subsidy of local health services, chronic disease control, vital statistics, hospital and nursing home quality control, environmental health programs and many, many more. There are state funds and local funds provided for some of these activities, as well as specific federal project grants for others. Nevertheless the 314(d) funds designed to fill the gaps in the whole spectrum of Public Health Services are not likely to be a source of large and significant funds for specialized Developmental Disabilities projects. At least 15% of the total 314(d) allocation is provided for the Mental Health authority in the state, which is often the responsible agency for mental retardation services as well. Because of this allocation, Public Health authorities may be inclined to refer requests relating to the developmentally disabled, to the Mental Health authority as the more appropriate agency for funding.

It is quite possible, however, that 314(d) funds could and should be utilized for strengthening and subsidizing those community services which comprise the major elements of Public Health Services and which are also very appropriate to the Developmental Disabilities client population: Public Health Nursing, and Home Health Services including Occupational and Physical Therapy and Home Health Aides. Since 70% of the 314(d) grant is to be spent in "local services" and since the Public Health/Nursing-Home Health program is usually the major component of local Public Health service, this would seem an appropriate use. The Developmental Disabilities client population, residing in a variety of settings in the community including their own family homes, independent living arrangements, and varying kinds of supervised residential care programs, are all eligible for the services of Public Health Nursing, as are all citizens of most communities. The Public Health Nurse has had special training above and beyond nursing in community work, communications, mental health, and the like. She is, if you like, the nurse in the social, not the medical care, context. Although varying in ability, as do all people and all professional types, she brings a variety of skills to a family or a developmentally disabled individual, and may serve as a key person in coordinating services to the individual and family, as well as in providing direct services herself. She will be knowledgeable about other community resources and can and should be working with schools, social workers, rehabilitation centers, and a variety of other helpers in putting together the total service needs of an individual.

Usually related to the Public Health Nursing program is the Home Health Agency, utilizing the skills of nurses, aides and other specialists in providing home care for eligible recipients. Eligibility for service is usually not a problem; eligibility for payment may be something else. Medicaid standards vary from state to state, state and local support to the Home Health Agency may be meager so that its services are limited. But through 314(d) funding, and through community support, these programs should be available to all developmentally disabled who might benefit from them. Home Health Services, extending and expanding the scope of home care beyond the traditional Public Health Nursing, are a relatively new development, having been given impetus by the passage of Medicare, which pays for Home Health Services for the elderly. Although obviously not appropriate for all developmentally disabled, the services have the potential to fill a number of gaps in the multitude of needs that must be met. The Home Health Aide can assist the mother of a disabled child, or may assist the developmentally disabled adult to remain in his own home, rather than have to seek residential care. She can assist with dressing, feeding, ambulation, baths and numerous other daily needs, under the general supervision of the Public Health Nurse. Other services that may be provided are the rehabilitation therapies, including occupational and physical therapy, either directly or through teaching of family members and/or home health aides. The program has great potential, particularly for the physically handicapped, which has only begun to be fully implemented and utilized.

Another major area of service which Developmental Disabilities and Comprehensive Health Planning should explore together is that of Early Detection and Evaluation. Through state and regional planning, and with the assistance of 314(d) funds, Title 19 funds, Maternal and Child Health Funds and Crippled Children's Services, it should be possible to establish regional centers to serve a geographic area, where infants and children are evaluated by an interdisciplinary team. Several such centers have been "pilot projects" in Minnesota and have performed effectively. The data from one of the Centers indicate that one-half of the children referred to the Center for "mental retardation" were not, in fact, retarded at all. The scope of evaluation must obviously be broad, including physical, mental, emotional and social factors. The outcome of evaluation must include an individualized program plan.

The base on which such an Evaluation Center is built may vary from region to region. It may be implemented through a school system, a medical center, a mental health center or stand alone. As it becomes known to the helping professions in its region, the Centers' services should be utilized more and more by a wide variety of referral sources. If properly implemented and publicized, we should no longer be confronted with the child whose first evaluation has occurred on entry to school, or who has never been properly evaluated at all.

The State Comprehensive Health Planning Agency has the statutory responsibility to see that the 314(d) funds are expended in accordance with Comprehensive Health Planning priorities. We must be sure that Developmental Disabilities plans for health-related services relate to the Comprehensive Health Planning priorities, and thus influence the use of the 314(d) funds.

ACHIEVING A MEANINGFUL PARTNERSHIP

If the role, intent and functions of the Developmental Disabilities Program and the Comprehensive Health Planning Program are similar and overlapping, how can we achieve a real partnership relationship? In state government, as in many other large enterprises, there are overlappings and functional relationships between many divisions, agencies, programs and departments. They cannot always be situated in the same agency side by side, because integration from one point of view may be fragmentation from another angle. If all services for the mentally retarded, for example, are integrated within a single agency, we are fragmenting the program of Special Education, Vocational Rehabilitation, Social Services, etc., all of which serve other client populations as well. The placement of the Developmental Disabilities Program has been a dilemma in many states, ours included.

If we consider that the primary function of the Developmental Disabilities Program is planning and coordination of services, then it is logical to place it where other such planning programs are situated, whether that is in the Planning Section of a Department of Human Resources, or a Planning Agency or Office, or, as in some states, in the Office of the Governor. In these settings there are advantages in the ready access to the executive decision makers, the "neutral" setting, in the assistance of other planners and coordinators performing similar functions, and in the close relationship with other programs such as Comprehensive Health Planning for all the reasons given previously. On the other hand, in the Departmental setting, related to the operating divisions concerned with mental retardation and/or physically handicapped, the Developmental Disabilities Program may accrue other advantages. Decisions that are made can be more directly implemented within the Division, the Developmental Disabilities Planning and Advisory Council can influence the program operators directly and change the way programs are developed and resources allocated. However, if placed within such a Division, the coordinative relationships with other operating agencies and planning programs are generally more difficult to develop and maintain.

Some examples can be cited which illustrate quite directly the commitment of a Comprehensive Health Planning agency to the goals and programs of Developmental Disabilities.

In Minnesota, at the state level, the Comprehensive Health Planning agency has provided the 25% match for the Developmental Disabilities Fiscal Year 1972 budget from a special legislative appropriation to Comprehensive Health Planning. The special appropriation was an award from the state legislature to implement and intensify comprehensive health planning efforts. Because of the resulting ability to provide the state match, and in recognition of its planning and coordinating role, the Governor of Minnesota responded to recommendations of the Developmental Disabilities Planning and Advisory Council and transferred the Developmental Disabilities Program from his office to the State Planning Agency. There the Comprehensive Health Planning and the Developmental Disabilities staffs are situated side by side and have the opportunity as well as the commitment to develop a real working partnership.

The Developmental Disabilities Planning and Advisory Council in Minnesota early expressed great interest and enthusiasm and established as a priority the development of regional planning programs. We have affiliated seven regional planning developmental disabilities planning councils with regional comprehensive health planning agencies. In most areas of our state, the comprehensive health planning agencies are the only regional human services planning groups existing, and provide a convenient base through which to operate. The matching funds have not generally been provided at the regional level by Comprehensive Health Planning, because of their own 50% local funds requirement. But the Comprehensive Health Planning staffs have, in general, written the regional grants, recruited the personnel and within a 6-month period have moved the Developmental Disabilities regional program to the point of implementation in three regions and very close to it in three more. One Developmental Disabilities regional group will affiliate with a Regional Development Commission, as will Comprehensive Health Planning, and one region is in the formative stages of regional organization. The organizational mechanics have been integrated so that separate incorporation as a non-profit corporation has not been necessary for the Developmental Disabilities regional planning organizations. Continuity beyond the initial year of funding is more assured, through the commitment of the Comprehensive Health Planning regional groups as well as the Developmental Disabilities Committees, no matter what the federal funding decisions are in Fiscal Year 1973.

The interaction at the regional level is fraught with problems. There are personality conflicts, power conflicts, issue conflicts, provider conflicts, and consumer conflicts. But they are persevering, problem solving, and through their combined efforts, will prevent the planning mechanism from becoming as duplicative and fragmented as the program mechanisms have become. After all, Developmental Disabilities was established to bring together the multitude of interests and services for the developmentally disabled. It should not, by its creation and existence, extend or perpetuate the fragmented, categorical approach which brought about the chaotic state of affairs in which we find ourselves today. There are power struggles within the Developmental Disabilities constituency itself, and it is not surprising that there should be conflict when a "partnership" relationship is being created.

In the last analysis, working together is a matter of commitment. Coordination implies willingness to modify one's activities and objectives in one way or another. There are those who give cooperation and coordination much lip service, but in practice do not relate, cooperate, or modify their objectives, with the result that coordination has no meaning at all. They will do their thing, come hell or high water, no matter how many Planning and Advisory Councils are created to relate their programs to others. On the other hand, there are those administrators and program personnel who understand that coordination may mean losing a little of their own independence, but who understand it also may mean gaining a better continuum or array of services for the client.

And this is surely the whole point. The developmentally disabled individual should be the final and overriding consideration. Where can we place this program, and how can we relate it to other programs so that the multitude of services, including prevention, early detection, rehabilitation, residential care and all the others, will be best programmed and delivered at the community level for those who need them? It would be great to see the major service systems put the client first and their own prestige and agency goals second! Life in the bureaucracy can be a series of power struggles and it is easy to lose sight of the reason for being in the game at all. Perhaps the Developmental Disabilities Program can help us all to focus on the developmentally disabled clientele more, and our own need for recognition less. The client and family should be at the center of the service systems, and the organization of the systems should relate primarily to consumer needs rather than to provider convenience.

Finally, since consumers often need a range of services from a number of different service systems, it becomes mandatory that those of us in the planning and coordinating business actually do plan and coordinate so that overlap and duplication are avoided and an appropriate and effective array of services is provided.

Use of Vocational Education Programs in Planning for The Developmentally Disabled

Frederick J. Weintraub

BACKGROUND

The federal role in meeting the vocational education needs of our youth is probably the oldest such intervention in the education system. Beginning with the Morril Act of 1862, the federal government has been a significant financial and policy force in the development of vocational education in our schools. There is little value in reviewing the vast number of Acts established by Congress over the years until 1963. But these acts could generally be characterized as piecemeal and directed at particular occupational interests.

In 1963 the Congress and the Administration sought to bring the disparate pieces together. The landmark Vocational Education Act of 1963 (P.L. 88-210) sought to provide

> "that persons of all ages, in all communities of the state . . . will have ready access to vocational training or retraining which is of high quality, which is realistic in the light of actual or anticipated opportunities for gainful employment, and which is suited to their needs, interests, and ability to benefit from such training."

Realizing that vocational education programs were becoming highly selective and not absorbing children with special needs, the Act also specifically provided that services be provided for

> "persons who have academic, socioeconomic, or other handicaps that prevent them from succeeding in the regular vocational education program."

The Senate report accompanying the Act went so far as to specify that it was their intent that the benefits of the Act were to be extended to children in state schools and institutions.

Three years after the passage of the Act the U.S. Office of Education published "A National Survey of Vocational Education Programs for Students with Special Needs."

Of the 51 states and territories that responded to the survey instrument, 12 reported having no vocational programs in operation for students with special needs. (The Office of Education included under the category of special needs the handicapped and the academically and economically disadvantaged.) Of the 24 states from which usable responses were received, 13 reported only one such program in operation in the state, 5 reported that there were two such programs, and the balance ranged from three to seven programs with 1 exception, Ohio, which reported 33 programs of vocational education for students with special needs. Nationally the investigators were able to identify only 79 such programs. Of the 79 programs identified nationally, 50 were located in comprehensive high schools, 21 in general high schools, and 5 in vocational high schools.

Sixty-eight percent of the "special needs" programs had a minimum level of ability or other qualification limitations for enrollment. This factor eliminated many students who could benefit from vocational education training. Fragmentary information suggested that vocational students tended to be substantially below other students in general academic performance. Yet, too often the vocational programs attempted to upgrade their student bodies and enhance their prestige, not by providing special help to those who needed it, but by actually eliminating such students by more stringent requirements.

Figures compiled by the U.S. Office of Education showed that in 1966, 1,238,043 persons were enrolled in vocational education programs throughout the country. Of this total, less than 1 percent were persons with special needs. In the 1965-66 school year, of all known expenditures for vocational education programs in the United States, only 1 percent of the funds were spent for youths with special needs. The inequity of this fact becomes more apparent when one considers that this population encompassed not only the physically, mentally and emotionally handicapped (comprising 10 percent of the school population) but also those considered academically and socioeconomically disadvantaged.

In partial response to the survey the Advisory Council on Vocational Education, in its 1968 report, "The Bridge Between Man and His Work," examined the direction that vocational education should take, and recommended that a substantial portion of vocational education funds be reserved for the "hard-to-reach" and the "hard-to-teach"; that admission requirements for vocational education be based on ability to succeed in a field of work, rather than on academic grades or rank in class; and that the general curriculum in effect be revised to meet the needs of the students which it is to serve.

THE 1968 VOCATIONAL EDUCATION AMENDMENTS

In 1968 the National Education Association and the Council for Exceptional Children, with the support of many national organizations for the handicapped, testified before the Congress calling for more specific provisions within the Act to assure handicapped children's participation in vocational education. In response Congress enacted the Vocational Education Act of 1968 (P.L. 90-576) which contained the following provisions:

- Reemphasized the intent that attention should be placed on "vocational education for handicapped persons who because of their handicapping condition cannot succeed in the regular vocational education program without special educational assistance or who require a modified vocational education program."

- Defined handicapped in the following manner: "the term 'handicapped,' when applied to persons, means persons who are mentally retarded, hard of hearing, deaf, speech impaired, visually handicapped, seriously emotionally disturbed, crippled, or other health impaired persons who by reason thereof require special education and related services."
- Created a National Advisory Council on Vocational Education and requires that a member of the Council be "experienced in the education and training of handicapped persons."
- Established State Advisory Councils on Vocational Education and requires that such Councils have a member "having special knowledge, experience, or qualifications, with respect to the special educational needs of physically or mentally handicapped persons." Members are to be appointed by the elected state boards of education or by the governors.
- Required that at least 10 percent of each state's allotment of funds (Part B) appropriated for any fiscal year beginning after June 30, 1969, shall be used only for vocational education for the handicapped. This section refers specifically to the grants to the states utilized to support basic vocational education programs.
- Amended the Education Professions Development Act to provide a special category of teacher training for vocational education through exchanges of personnel, inservice training for teachers, short-term institutes, and fellowships. Particular note was made that such training be extended to programs for the handicapped.

The Senate in its accompanying report expressed concern that there would be three major impediments to effective delivery of vocational education services to handicapped children: facilities, limited scope of existing programs and coordinated planning. To counter these they required that the U.S. Office of Education undertake the following 10 activities.

1. That a survey of existing vocational education facilities be undertaken to determine their accessibility to the handicapped.

2. That the Office of Education establish mechanisms for insuring that new vocational education centers comply with regulations prohibiting architectural barriers.

3. That a comprehensive study be undertaken to examine ways of adapting physical plant, equipment layout, machinery, and so forth, to the unique vocational education needs of the handicapped. Based on the findings of this survey it was recommended that experimental and demonstration centers be established to evaluate modifications and disseminate such information to the field.

4. That the Office of Education provide the leadership and expertise in assisting State and local public school agencies in developing curriculum plans and materials in order to meet the unique vocational education needs of the handicapped.

5. That the Office of Education encourage other agencies and disci-

plines to provide ancillary services for the handicapped in vocational education programs.

6. That expansion of vocational education on the elementary and post-high school levels be further emphasized for the handicapped, in that such programs necessitate a long-term process, from the development of work attitudes in the early school years to counseling and retraining following high school.

7. That all State vocational education agencies be required to develop jointly with the State special education agency a comprehensive plan for providing vocational education to the handicapped and that this plan be coordinated with the general State vocational education plan.

8. That plans for vocational education for the handicapped consider the needs of such persons in day and residential facilities whether public or private.

9. That State plans consider the unique problems of educating handicapped persons in rural or urban communities. It was suggested that the use of regional vocational education centers be considered, including regional residential schools for children with low incidence disabilities.

10. That efforts be undertaken in each State to coordinate the activities of vocational education, vocational rehabilitation and special education.

WHAT HAS HAPPENED SINCE 1968

In 1970 115,219 handicapped children received vocational education services under the provisions of the Act. In that same year 8,738,960 children were served. In 1970 $1.8 billion was spent totally on vocational education with 53.8 million going to the handicapped or only 3 percent of the total monies, and 8 percent of the Part B funds.

In 1971, the number of handicapped children served increased to 208,681 of the total population served of 10,495,411 with expenditures for the handicapped increasing to $60.7 million or 2.64 percent of the total expenditure and 10.7 percent of the Part B funds. Presently the handicapped comprise less than 2 percent of the total vocational education enrollment.

The members of the National Advisory Council were appointed including a spokesman for the handicapped: presently Delfino Valdez. In the first 5 reports of that council detailing the problems facing vocational education and proposing solutions, no significant mention was made of vocational education for the handicapped.

Each state has an Advisory Council with a member representing the interests of the handicapped. A review of the 1970 reports of the State Advisory Councils shows that very few state councils had given serious consideration to the handicapped nor were they recommending improvements in this regard.

To the best knowledge of the author, practically nothing has been done to date to carry out the 10 activities required by the Senate, particularly those relating to facilities and coordinated planning.

HOW THE PROGRAM IS ADMINISTERED

At the federal level vocational education is administered in the U.S. Office of Education by the Bureau of Adult, Vocation and Technical Education. Provisions for the handicapped and the disadvantaged are administered by the *Special Needs Branch.* While *BAVTE* does administer and is responsible for the program, a review and collaborative function is maintained by the Bureau of Education for the Handicapped.

At the state level the program varies from state to state, but is always under the state education agency–although in some states policy is delegated to a board different from the state board of education. Every state has an individual designated as the director of vocational education.

In most states the special education agency in the state is playing an instrumental rôle in setting priorities for the funds set aside for the handicapped and in reviewing proposed projects. This information is conveyed to USOE through the "projected activities form," by the states under Title VI of the Elementary and Secondary Education Act.

After reviewing over 150 vocational education programs for the handicapped considered by the states to be exemplary, the author found the majority of such programs to be directed at the mildly retarded and those with sensory handicaps. Twenty-three programs in 17 states could be construed as serving developmentally disabled children with substantial handicaps. While the programs varied substantially, the following examples may be helpful.

Eastern Arizona Training Center
Box 1467
Coolidge, Arizona
Number of students: 32
Type of handicap: MR

Thirty-two mentally retarded students who had been institutionalized for an average of 5 years, and some for as long as 12 years were selected for enrollment in this project as a result of testing and in-depth interviews. The ultimate purpose of the project is to help these students, and others like them, who would otherwise be destined to live in an institution, to become self-sustaining citizens capable of maintaining themselves in community life.

Vocational classes are being provided in the areas of agriculture, home economics, and trade and industry. Through counseling, evaluation, job placement and follow-up, the vocational teachers are providing each student with the maximum opportunity to progress at his own rate, to the fullest extent of his capabilities.

Academic instruction focuses on the total learning required for a student's successful employment. Since many of the students were found to be lacking the interpersonal relations skills required for community living, these are included in the course of study, along with instruction in employer's expectations, and attitudes for job-getting and job-keeping.

An assessment of the progress made thus far by the students originally enrolled reveals that a total income of $4,280 has been earned, and that 11 students are in full time community training or employment, 10 part-time employment, 7 have been referred for placement in the community or returned home, and 5 have received commitments for employment in the immediate future.

Los Lunas Hospital and Training School
Los Lunas, New Mexico
Number of students: 95
Type of handicap: EMR, TMR

Vocational Horticulture Program

The objective of this program is to train mentally retarded students for employment in greenhouse operations in the surrounding area.

The course of study covers three areas of horticulture: greenhouse and nursery growing, landscape maintenance and floral assisting.

In training as a greenhouse and nursery grower, the student learns to identify plants, and is instructed in growth habits, plant propogation, cultural practices, soils, insect and disease control, and the maintenance of horticultural structures.

In landscape maintenance, the student learns maintenance of lawns, flower beds, trees and shrubs, and landscape planning.

The floral assistant course is designed to prepare the student for work in a florist's shop.

In each of the areas, students receive classroom and individual instruction, and are given laboratory practice in the greenhouse on the grounds of the school. Ultimately, they are placed in one of the horticulture businesses in the area to gain practical experience.

Greenville County Schools
Greenville, South Carolina
Number of students: 48
Type of handicap: TMR

This program was established to meet the needs of those students who would be eligible for vocational rehabilitation, sheltered workshop activity and on-the-job training for possible job placement in the community. A base line on each student, both in the area of potential skills and social adjustment is established, then a program and methods for implementing it for each student is developed to obtain the specific goals set for him. Instruction includes training in basic work habits, personal hygiene, simple language arts, finance management, use of community facilities for leisure time, basic occupational and living safety, personal and social adjustment, and development of motor skills.

Methods utilized depend upon base lines developed, but generally are situational in order to minimize the dependence upon transfer and insight.

The major program objectives are: (1) to give training in basic work skills in selective position categories: (a) simple assembling work relating to contracts; (b) building and grounds–maintenance; (c) food service; (d) developing physical coordination, and (e) domestic service; and (2) to evaluate by vocational tests and performance and aptitude tests.

A review committee evaluates the effectiveness of the program. The committee is composed of representatives from Greenville County Public Schools, South Carolina Employment Security Commission, South Carolina Department of Mental Retardation and Greenville Association for Retarded Children. Students are placed in jobs by the Director of Piedmont Skills.

Intermediate School District 109
Snohomish County Courthouse
Everett, Washington 98201
Number of students: 110
Type of handicap: TMR

The Washington State Departments of Special Education and Vocational Education are cooperatively funding and conducting this program which provides handicapped youths with supervised, sheltered, prevocational, and exploratory paid work experiences. Work stations are maintained at four sheltered workshops in the county.

Emphasis is placed upon helping the students to develop a wider variety of work skills, to make more informed choices about types of work activities preferred or disliked, and to develop physical abilities, language skills and confidence.

Woodrow Wilson Rehabilitation Center
Fishersville, Virginia
Number of students: 1,359
Type of handicap: MR, CR

The objective of the program is to prepare handicapped students for employment in trade and industrial and business education fields. Instruction is provided in typewriting, shorthand, accounting, bookkeeping, general office practice, auto body repair, auto mechanics, auto servicing, barbering, cosmetology, drafting, electricity, electrical appliance and motor repair, food service, furniture refinishing and other skills.

Twenty-five percent of the instructional time of students is spent in formal and classroom instruction, and 75 percent in laboratory experiences, with some students provided work experience. The students may enter most occupational programs each month of the year.

The supervisory and instructional staff include 2 supervisors, 4 business and office education instructors, 32 trade and industrial instructors, and 12 prevocational instructors.

All participating students have been selected by field representatives of the Virginia Department of Vocational Rehabilitation as eligible for rehabilitation services. They include those of low IQ, as well as those with all types of physical handicaps.

A more recent development at the Center is an additional prevocational program designed to give experience to prospective students in advance of their being assigned to a training area. The students spend several weeks in this section, rotating through various experiences, and being evaluated in terms of training for which they may have attitudes, abilities, and interest.

The program is operated by the Virginia Department of Vocational Rehabilitation with the cooperation of the Vocational Education and Special Education Division of the State Department of Education.

Rock Creek Center
Route 1
Frederick, Maryland 21701
Number of students: 23
Type of handicap: TMR

This is a special work-study program to help students aged 15-18 to make a transition from the school to the community.

Twenty-three are assigned to work stations for a period of 6 weeks. The work day lasts for approximately four hours. Each day, a period is set aside for the teacher to have an opportunity to discuss the day's work experience with the student. At the close of the 6-week period, the trainee returns to the classroom for 6 weeks of needed supplemental classroom instruction. Then, the student is given a second 6-week assignment at a work station. During periods spent at work stations, the students are transported by the regular school bus, and are inspected for grooming each day before work.

The classroom program includes units of instruction in health and safety, social development and adjustment, grooming, family living, community living and occupational information. The curriculum includes instruction in the qualities of a good worker, requirements for work permits, how to fill out employment applications, deductions made from wages and why, fringe benefits, mock job interviews, an understanding of budgeting and banking, and the development of a good self-concept. Evaluation consists of the following: (1) a coordinator visits various employers at least once a week for a conference; (2) frequent spot checks of pupils are made; this keeps the student aware of his responsibilities to his school and employer. Also, it provides the teacher with information regarding the needs of the pupil so that these needs can be met during the school class session; (3) employers are asked to fill out evaluation forms twice during the 16-week interval so that strengths and weakness can be noted and (4) both individual and group counseling are conducted, so that students may benefit from each others' experiences.

This program has brought about a noticeable change in the role of these young people in the community and in attitudes of members of the community. There has been a decline in the number of drop-outs, and an increase in self-confidence, mutual respect, and sense of pride. Examples of the types of jobs being learned by those students are: mechanics, day-care aides, maintenance, motel maids, domestic help, aides at rest homes for the elderly, and busboys. One measure of success of the program is that many employers request that the student come to work for them full-time after they finish school.

An important ingredient to the success of the program has been the support of the community at large, and especially the support of the employers.

Fargo-Moorehead Evaluation and Training Center
424 South 9th Avenue
Fargo, North Dakota 58102
Number of students: 75

Type of handicap: TMR

The local public schools' responsibility for career education is emphasized by the Fargo Public Schools. On April 1, 1970, the private, nonprofit Fargo-Moorehead Vocational Training Center, Inc., became a part of the Fargo Public School System, expanding the continuum of services to the handicapped from early education to job training and placement.

This program provides such interrelated activities as vocational evaluation, job training, private tutoring in academic skills, training in grooming and social graces and other skills necessary for independent living, supervised recreation, and a supportive counseling and guidance service.

The vocational evaluation unit assesses the abilities of over 300 handicapped individuals each year through psychological, sociological, and vocational evaluations, which take from 4 to 10 days. The referring agency is responsible for the $75 fee and receives a written report of the complete evaluation.

Evaluated clients may the be placed directly by vocational rehabilitation or may be recommended for the transitional workshop. The first 3 months attention is focused upon diagnosis and evaluation so that the staff can determine the feasibility of immediate or eventual job placement, and set the training goals for prevocational training. Client production is emphasized using real work as the training vehicle. Work assignments are given on the basis of trainee need and as an avenue of meeting established objectives. Supportive counseling assists the trainee in learning to be productive which, in actuality involves a change in the self-concept. Augmenting the production training, trainees participate in supervised recreation, grooming and social graces classes, private tutoring in academic skills and speech therapy, training in independent living skills emphasizing responsibility for maintenance costs and leisure time activities, and participation in job tours.

When progress in prevocational training is sufficient to attempt competitive job experience, a transitional on-the-job placement is provided that is geared to the overall requirements and needs of the individual. Graduation comes when there is reasonable job adjustment and the prospect of continued employment.

If a potential client does not demonstrate sufficient ability to profit from the transitional workshop, he may be placed in the extended sheltered workshop, maintained on the center's premise by the Fargo-Moorehead Vocational Training Center, Inc. The sheltered workshop goals still center around the client and his eventual placement in a competitive job situation.

Because the center serves handicapped persons from Minnesota as well as North Dakota, housing becomes an important factor in the success of the program. Counselors and a social worker find foster placement for new trainees. As they demonstrate their competencies, trainees are placed in a private apartment (where the landlord provides a paternal eye). Thus, handicapped persons used to a sheltered environment expand their abilities and responsibilities in an atmosphere of positive growth with only enough support to enhance the chances of success.

Several additional factors play an important role in the success of the Evaluation and Training Center. These include: (1) the Fargo High School work-study program, where retarded teenagers spend a half day in the high school and a half day in the center; (2) the important coordination between special education, the center, vocational rehabilitation, the veterans administration, mental health center, social security, workmen's compensation board, the manpower center, and the model city program. Ten years of practice in training and placement of the handicapped has created a well trained and mutually supportive staff necessary for handling the complex factors essential to developing human potential.

WHAT CAN YOU DO?

1. Determine how your state is presently carrying out its 10 percent obligation for the handicapped. In doing so, consider the following:

a. To what extent are they offering a wide variety of vocational training opportunities to the handicapped? Many programs limit the handicapped to only one or two vocational opportunities.

b. To what extent have they integrated the handicapped into and expanded the total vocational education programs? There should be available three types of programming for the handicapped: (1) integration into the regular vocational education programs, with necessary adaptations in the physical environment; (2) Integration into the regular vocational education programs, with necessary adaptation of the teaching strategies and supportive assistance; and (3) special vocational education programs for the handicapped. It should be emphasized that the 10 percent set aside should be limited to the special program costs incurred as a result of serving the handicapped– not to support present general vocational education services.

c. To what extent are vocational education agencies, in conjunction with state employment agencies and state commissions on employment of the handicapped, seeking increased job opportunities for the handicapped? Without such efforts training will continue to be limited to known placement opportunities.

d. To what extent are admission standards to vocational education relevant to the skills necessary to learn and perform effectively in a particular job? Presently standards such as IQ scores and academic grades prohibit many handicapped children from access into programs in which they could function effectively.

e. To what extent are they utilizing the full job training capabilities of a community? Most communities have a variety of agencies and programs for developing vocational skills. Rather than purchasing such services, the general vocational education program has sought to develop such programs within comprehensive high schools or vocational-technical high schools. This practice has been reversed in regard to the handicapped. Caution should be taken to assure that handicapped children are not simply dumped outside the vocational school system when such placement is not necessary. On the other nand vocational education should be encouraged, in terms of their total program, to utilize total community services, but not in a discriminatory fashion.

f. To what extent are present training programs for the handicapped realistic and directed to placement outside of the training center? It appears as if some programs, particularly those in institutions are no more than the present peonage system. It is appropriate to train institutionalized individuals as groundskeepers, for example, if such training leads to employment within or outside the institution. However, the goal should be for the benefit of the individual and not solely for the institution.

2. Determine how your state vocational education agency is exercising a leadership responsibility to assure that local programs include the handicapped. This should be conveyed through strong policies, consultative assistance and penalties, if necessary.

3. Determine how funds under vocational education can be coordinated with vocational rehabilitation, special education and the vast number of other manpower development programs in your state to assure that each handicapped individual has available the necessary prevocational, vocational and retraining opportunities to assure their maximum occupational development.

Opportunities Through HUD Funding of Residential Facilities

Mercer L. Jackson

In November of 1971, the President called upon Federal agencies to support the prevention of mental retardation and to help the mentally retarded return from institutions to the community. Acting on this mandate and other related areas of recognized need in March, 1972, Secretary George Romney established within his office an Assistant to the Secretary, Programs for the Elderly and the Handicapped. With these actions, a period of slow awakening to the special needs of the handicapped gained both direction and momentum.

It was through 1964 amendments to the National Housing Act and the Housing Acts of 1937, 1959 and 1961 that eligibility of the handicapped for Federally-assisted housing was first established. Supportive action over the years has been positive but limited. American National Standards Institute Specifications for buildings and Minimum Property Standards for housing specifically designed for the elderly and the handicapped have been established. A study was completed leading to the publication in 1968 of a HUD guidebook on design of housing for the handicapped.[1] Five housing projects were provided strictly for the handicapped under federally assisted programs, and many federally supported housing units have been constructed to specification for the elderly and the handicapped.

As a related action, following the enactment of P.L. 90-480, the Architectural Barriers Act, HUD and other federal agencies initiated programs to ensure a barrier free environment in public buildings and federally supported housing (except privately owned housing) for the elderly and the handicapped. This ongoing effort will continue indefinitely until our man-made environment becomes compatible with the need for full mobility of our handicapped population.

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[1] The five demonstration projects for the handicapped include: the Omaha, Nebraska Association for the Blind; the Pilgrim Lutheran Church Home for the Deaf, Los Angeles, California; the Fall River, Mass. Hussey Hospital Project and the Toledo, Ohio demonstrations seeking alternatives to institutionalization; and the Seattle, Washington project for those with mixed physical handicaps.

The Presidential mandate regarding the mentally retarded, together with existing housing statutes, permits us to build upon these past actions and to seek new and innovative solutions and wider application of existing programs for housing for the handicapped. An examination of existing programs will be helpful.[2]

HUD presently administers a wide variety of housing and health care facility programs which may be classified as either subsidized or unsubsidized. The unsubsidized category includes those programs in which federal assistance is limited to insurance of the mortgage. Private and multi-family residences, intermediate care and skilled nursing homes, hospitals and group (medical) practice facilities are examples of the unsubsidized programs.

There are two basic subsidized programs established under different acts, the low rent public housing program and the mortgage interest subsidy and rent supplement programs. These have similar objectives but differ in methods of application and in eligibility requirements.

First, low rent public housing is administered through officially constituted local public bodies established under state law which are referred to as local housing authorities. Utilizing federal programs, administered by HUD, they obtain housing (new construction, rehabilitation and lease) through the sale of local bonds which are then retired by the annual contribution of federal funds. This concept is distinctive in its service to the lower income groups and the regulations under which it operates. It can offer homeownership as well as rentals.

Secondly, the mortgage interest subsidy programs serve both the homeownership and multi-family rental needs, but they are dependent upon initiatives in the private sector for their development, financing and management. Corporations, limited dividend, and nonprofit sponsors, utilizing the Sections 235 (homeownership) and 236 (rental) programs, provide housing for the moderate income levels. Federal subsidy payments are made directly to the mortgagee so that mortgage payments can be maintained at below market levels.

Rent supplements are authorized to be used in conjunction with the Section 236 rental program and certain selected unsubsidized rental programs (202, 231 & 221(d)(3)) as a means of further adjusting rents to meet the capacity of lower income tenants.

For the remainder of this presentation we will concentrate upon rental programs and simply note that eligibility for the Section 235 (homeownership) program is based entirely upon adjusted income. Handicapped persons are eligible.

In examining opportunities for the handicapped within HUD subsidized rental programs, we must first acknowledge several specific eligibility requirements based upon income and definition of the handicapped.

The statutory definition of handicapped set forth in Section 202(d)(4) of the Housing Act of 1959, as amended, states that:

> The term '* * * handicapped families' means families which consist of two or more persons and the head of which (or his

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[2] HUD programs are quite varied and cover a wide range of needs from single-family to multi-family and independent living to skilled nursing care facilities. A brief listing of HUD administered housing programs is attached.

> spouse) is * * * handicapped, and such term also means a single person who is * * * handicapped. A person should be considered handicapped if such person is determined, pursuant to regulations issued by the Secretary, to have a *physical impairment* which (a) is expected to be of long-continued and indefinite duration, (b) substantially impedes his ability to live independently, and (c) is of such a nature that such ability could be improved by more suitable housing conditions. [Emphasis added.]

This definition of "handicapped" is relevant to the admission of handicapped persons authorized under Section 231, 202, 221(d)(3), 236 and the Low Rent Public Housing Program. In addition, if he is disabled, (defined as the inability to engage in any gainful activity by reason of any medically determinable *physical* or *mental* impairment which can be expected to last for a continuous period of not less than 12 months) he also qualifies but only under the low rent public housing program.

The Department's original interpretation provided that the Section 202(d)(4) definition of handicapped, which was based on "physical impairment," did not include the mentally retarded. The Department's present position, however, is that if the mental retardation of an individual can be determined to be the result of a physical impairment, such as a brain damage problem, or chemical or neurological physical impediment to normal growth, then that individual legally could be considered "handicapped" for purposes of determining eligibility.

Although federal programs can provide housing projects for the handicapped, other limitations in living arrangements and the intended purpose to be served by a subsidized project must be recognized. Projects designed to provide institutional care are not authorized. Rental housing projects under these programs cannot be of the dormitory type and must provide separate accommodations for each tenant or tenant family. Shared facilities may include kitchens and community space. However, certain restrictions apply in the case of shared bath or toilet facilities. Also, each project must receive an administrative determination as to management and financial feasibility.

HUD does not provide management or services but exercises essential interest in such matters through regulatory agreements.

Medical, in-patient and out-patient care and congregate meal services may be provided within such projects. However, the cost of necessary medical equipment, the food and materials being provided and the cost of delivery of services may not be subsidized or included within the mortgage. In public housing, the annual contributions contract may not include such costs.

In addition to the eligibility requirements for admission of the handicapped, there are income and in certain cases, asset limits that must be met. These vary from one geographic location to another because of variations in cost of living and other economic considerations.

It should be noted that accommodations for custodial or companion associates essential to the functional needs of the handicapped person may be provided for in all HUD programs.

Of special interest when serving special groups is the type of housing and services. Most of HUD resources are directed to housekeeping units to provide completely independent living. However, the 1970 Housing Act provided for congregate housing in three rental programs: Public Housing, Section 236 and Section 221. Congregate housing is characterized by a full central food service and other services needed by more frail or handicapped persons. The key to the success of congregate housing is the provision and assurance of continuity of the needed services and the ability of tenants to pay for these services. In addition, sensitive design and special management staff will be required. The concept of congregate housing is to fill the gap between the ability to live a completely independent life and premature resort to a medical facility. Well conceived, adequately financed and well managed congregate housing holds promise as one alternate to more costly and less desirable institutionalization for many.

It is probably clear at this point that although our programs are available to serve the handicapped, the complicated array of technical requirements demand close study and consultation with specialists in the HUD field offices.

Our experience in the sociological and psychological aspects of housing the physically handicapped is limited. We have long emphasized a policy that concentrations of handicapped individuals can, in many situations, be undesirable for the tenants. Thus, we have, encouraged the mixing of handicapped tenants with the nonhandicapped. The similarity of design for the elderly and handicapped plus the extension of the sections of the Acts establishing eligibility for the elderly to include the handicapped has brought about combined elderly and handicapped developments.

With the advent of an increased variety of handicaps to be served within HUD programs, we recognize that variations will be common. In this regard, we intend to proceed cautiously with assistance from several disciplines, as we attempt to serve all eligible tenants.

The Administration has initiated and is now aggressively pursuing several actions to improve responsiveness to the needs of the handicapped and to consolidate and simplify the administration of programs. The following are of interest:

- A legislative proposal to consolidate and simplify the National Housing Act programs has been submitted to the Congress each year for the past 2 years by this administration. While not specifically directed to the benefit of the handicapped the improvements would greatly enhance our ability to serve this population group.
- A research and demonstration project has been conducted with the local public housing authority and the Hussey Hospital in Fall River, Massachusetts to examine alternatives to institutionalization of handicapped persons. The final report will be issued within the new few weeks.
- HUD has recently approved two Section 236 projects for the mentally retarded, to be operated by the State of Michigan.
- HUD is developing a special numbering and reporting system which will identify housing for the handicapped under all HUD programs. Future statistical reports will reflect both the activity and interest of sponsors in such housing permitting an analysis of the variety and diversity of solutions being proposed or funded.

- HUD is working in close cooperation with the Rehabilitation Services Administration in development of research and guidelines for HUD field offices in the considerations to be observed in the approval of housing for the handicapped. One of the early projects will be to assess the existing HUD supported projects housing the handicapped in order to relate that experience to our future endeavor.
- HUD is cooperating with HEW in that Department's search for alternatives to institutionalization.
- Research proposals being entertained now include one calling for barrier free site design of handicapped housing projects and one dealing with special housing design and special housing facilities for severely handicapped individuals.
- HUD is assisting in a study for utilizing technology to aid the handicapped, a subject of special concern to the President and initiated by his Office of Science and Technology. The President in his Health Message to the Congress on March 2, 1972, committed his Administration to use "the skills that took us to the moon and back" to develop devices "to help the blind to see, the deaf to hear and the crippled move." Involved in this study are the following Departments; HEW, Defense, Commerce, HUD, DOT, AEC, National Aeronautics and Space Administration, Veterans Administration. The National Science Foundation also is participating.
- HUD has appointed specialists in programs for the elderly and the handicapped at all levels and in all field offices. Training for such specialists is in progress.
- Secretary Romney has agreed to support a study of new, revised American National Standards Institute specifications for housing for the handicapped.

These actions and proposals for future actions are indicative of the new momentum and the intent to serve the handicapped. We are pleased to have this opportunity to report our activities and our capacities to the National Advisory Council for the Developmentally Disabled, and we will welcome your close association and support in these efforts.

SELECTED HUD PROGRAMS FOR THE HANDICAPPED

While most of the approximately 40 active mortgage insurance programs administered by the Federal Housing Administration are available to the handicapped, provided they meet other eligibility requirements, the programs outlined below have specific provisions designed to meet the needs of the handicapped.

Low Rent Public Housing: HUD authorizes properly constituted local housing authorities to obtain, manage and maintain housing facilities for low income families at rents they can afford. Funds are raised through the sale of local bonds which are then retired through federal funds on an annual contribution basis. Housing programs include single-family detached and multi-family units which may be rented or rented with option to buy. The Section 23 lease provisions permit the housing authority to lease privately owned housing or apartments for rental to low income families. Income and asset limits for prospective occupants are determined locally and approved by HUD. Rental rates are scaled by size of family, number of bedrooms and income, with rents limited to not more than 23 percent of adjusted income. The program serves the lower income levels.

Section 202: A program serving the elderly and the handicapped in the moderate income scale. This program has been phased into the Section 236 program.

Section 221(d)(3): Privately owned, federally insured, multi-family rental projects for the elderly, handicapped and displaced. Specific projects may be authorized to accommodate tenants receiving rent supplement payments.

Section 231 (Elderly and Handicapped) Housing: Basically an unsubsidized, mortgage insurance program, operating at market rent levels. Rent supplement may be authorized in such projects.

Section 232 (Nursing Homes and Intermediate Care Facilities): Skilled nursing homes and intermediate care facilities may have mortgages insured by HUD, subject to specific regulatory requirements and a state certification of need.

Section 235: A mortgage interest subsidy program to enhance homeownership for the low and moderate income family. Purchases may include single-family, condominium or cooperative units within statutory cost limits.

Section 236: HUD authorizes private sponsors to construct or substantially rehabilitate multi-family projects for rental to the moderate income group. Subsidy of the mortgage interest, down to a level of 1 percent is provided as a means of reducing rents. Eligible tenants will be expected to pay the basic rent (rate made possible by full application of the subsidy) or a greater amount, where the level of individual income permits. This program serves an income level about 35 percent higher than that served by public housing.

Rent Supplements: Low income persons and families who are either elderly, handicapped, displaced by Government action, occupants of substandard housing or former occupants of homes damaged by natural disaster, are eligible to receive rent supplement payments. Rents are based upon adjusted income with supplemental payments provided by HUD. The income level of eligible occupants is comparable to that in public housing. The majority of contract authority made available by the Congress in recent years has been allocated to Section 221(d)(3) market interest rate projects and to selected Section 236 projects. A small part of the contract authority also has been allocated to State aided projects. Although the Section 221(d)(3) BMIR and the Section 202 programs have been phased into the Section 236 program, there are approximately 5,500 units in the two programs which continue to receive rent supplements.

FIELD OFFICE JURISDICTIONS

U.S. DEPARTMENT OF HOUSING AND URBAN DEVELOPMENT

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RICHARD C. VAN DUSEN, UNDER SECRETARY

October 2, 1972

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Services Available to The Developmentally Disabled Through the Bureau of Education for the Handicapped

Thomas Irvin

INTRODUCTION – PURPOSE

The Federal government made its first foray into the education of the handicapped in 1954, when President Eisenhower signed the ***Cooperative Research Act****. In 1957 Congress earmarked $675,000 of its first million-dollar appropriation for research related to the education of the mentally retarded. In 1958, it provided for a comprehensive program to caption films for the deaf and one to train professional personnel to work in the education of the handicapped. By 1963, there were enough Federal programs supporting such efforts to make it worthwhile to establish in the Office of Education a separate Division of Handicapped Children and Youth, and in 1967 that Division was made into the Bureau of Education for the Handicapped. With the passage of P.L. 91-230 on April 13, 1970, all major Federal legislation relating to the handicapped was consolidated into a single* ***Education for the Handicapped Act****. And this legislative action formally recognized the handicapped as a distinct population with just claims to a share in the nation's resources.*

It is the responsibility of the Bureau of Education for the Handicapped to administer this law.

The purpose of this paper, as implied in the Title, is (1) to present an overview of those programs within the Bureau of Education for the Handicapped which support educational activities and services for developmentally disabled children, and (2) to present BEH major objectives and strategies.

BEH BACKGROUND

The Bureau of Education for the Handicapped (BEH) is one of seven major operating units within the Office of Education (The Office of Education is one of the basic agencies within the Department of Health, Education and Welfare). It has the distinction of being the only Bureau within the Office of Education that was legislated into existence. The 89th Congress took this unusual step because of a recognized need to have a single, top level administrative unit within the Office of Education which would be responsible for the administration and coordination of all programs or components of such programs which directly affect the education of handicapped children.

Organizationally, BEH is comprised of the Office of the Associate Commissioner (which includes the planning, evaluation and management functions of the overall Bureau) and three major operating divisions: A Division of Training Programs, a Division of Research, and a Division of Educational Services. The various programs or funding authorities administered by these three divisions will be presented in the following pages.

DIVISION OF TRAINING PROGRAMS

The Division of Training Programs (DTP) administers one of the oldest categorical programs in the Office of Education. This program was authorized by Congress in 1958 under Public Law 85-926 (Training of Leadership Personnel in the Education of Mentally Retarded Children). It was amended several times, but most notably in 1963 when President Kennedy signed Public Law 88-164 (The Mental Retardation Facilities and Community Mental Health Centers Construction Act). Section 301 of that act amended P.L. 85-926, to authorize the training of personnel in all areas dealing with handicapped children. The program is now referred to as Part D, Education of the Handicapped Act.

The Division of Training Programs provides program assistance grants to State departments of education and over 300 institutions of higher education for the training of personnel in the education of handicapped children. Grants are also available to colleges and universities (only) for the training of physical education and recreation personnel to work with the handicapped.

In addition to the above program assistance grants, the Division also administers a special projects program. The purpose of this program is to plan for, experiment with, and evaluate the effectiveness and efficiency of new models in preparing personnel to educate handicapped children. These types of projects are expected to result in programs which can better meet the manpower needs in the field of special education. State education agencies, institutions of higher education and other non-profit and private agencies are all eligible for participation in this program on a discretionary basis.

The DTP also earmarks funds each year (currently $800,000) to support part of the cost of the special education dimension in 18 of the university affiliated facilities. Usually the funds have been used to support a director of special education within the centers. (Construction and core operating support for these Facilities is authorized in the Developmental Disabilities Act, P.L. 91-517).

The overall budget for FY 1972 for training program is $35 million. An estimated 22,000 personnel will be trained as a result of this program. At present, it is impossible to estimate the actual number of dollars that have been earmarked or the total number of personnel to be trained for the developmentally disabled. However, high priority has been assigned to programs preparing educational personnel for multi-handicapped, severely and profoundly retarded, autistic, and learning disabled children. Many of the children in these sub-populations are included in the developmental disabilities definition.

Some college training programs preparing special teachers under this authority are also beginning to focus more and more on direct hands-on involvement with handicapped children in the classroom setting, as a basic, on-going part of the training program. For example, at the University of Wisconsin, the program training teachers for severely mentally retarded children is conducted primarily in a local Madison Public school for the trainable mentally retarded. The children in the program are severely retarded, some not toilet trained; and some have been excluded from the more traditional special educational programs. This type of preparation, begun early in the teachers' training, should have a real pay-off in terms of better prepared teachers who really know from experience how to work with the severely retarded.

DIVISION OF RESEARCH

The Division of Research, as the name implies, is responsible for the administration of research, innovation, and demonstration programs designed to improve educational opportunities for handicapped children. The Division supports investigators and organizations in the discovery, organization, and sequencing of knowledge for the maximum educational benefit for the handicapped.

The current (1972) budget for this program is $15½ million. Approximately 135 projects are being support with these funds. It is estimated that nearly one-third of the projects focus on or include children who are developmentally disabled. Following is a listing of some of the projects currently being supported:

1. Responses Pattern in Brain Damaged Children and Teaching Styles
2. Coordination and Integration with Day Care Agencies of In-Patient and Out-Patient Education and Evaluation
3. Programmatic Research Project in PE for the Mentally Retarded Child in the Elementary School
4. A Program Project, Research, and Demonstration Effort in Arithmetic Among the Mentally Handicapped
5. A Center for Innovation in Teaching the Handicapped
6. A Diagnostic Physical Education Center for the Trainable Handicapped Children
7. Determining Criteria for Assessment and Remediation Procedures in Selected Developmental Physical Skills of Trainable Mentally Retarded & Multiple-Handicapped Pupils
8. A Study of Behavioral Change in 50 Severely Multi-Sensorily Handicapped Children Through Application of the Video-tape Recorded Behavioral Evaluation Protocol
9. Project on the Classification of Children
10. A Demonstration of Three Models of Advocacy Program for Developmentally Disabled Children

DIVISION OF EDUCATIONAL SERVICES

The third division with BEH, called the Division of Educational Services, provides distribution of resources to assure that educational services for the handicapped can be initiated, expanded, or extended at the state and local levels. Nearly 75 percent of the Bureau's total budget is administered in this Division. The Division is also unique in that the majority of its funding authorities include child centered, direct service programs. That is, instead of the funds being used to support training or research activities per se, they focus on providing direct educational and related services to individual handicapped children.

The Division is divided into three major units: Media Services and Captioned Films Branch, Program Development Branch, and Aid to States Branch. The various programs administered under each of these three branches are described in the following pages.

Media Services and Captioned Films Branch

The media services and captioned films program is essentially self explanatory. The original authority, the Captioned Films for the Deaf program (P.L. 85-905), was authorized by Congress in 1958; and it was extended in 1968 to include provision of media services for all types of handicapped children.

In addition to the captioning of educational and recreational films, this branch also supports: (1) four Regional media centers for the deaf, (2) thirteen instructional materials centers serving all types of handicapped children,* and (3) the National Center for Educational Media and Materials in Columbus, Ohio. This center is concerned with the development, validation, field testing and dissemination of educational materials for all handicapped groups.

*It is worth noting that over 300 associate instructional materials centers have been established as adjuncts to the 13 Centers through State, local and other Federal funding resources.

The FY 1972 budget for the Media Services and Captioned Films Program is $13 million. It is impossible to estimate at this time the amount of those funds being used with the developmentally disabled population. But, it is clear that this program has significant potential for DD children; and it should be pointed out that high priority has been assigned within the Branch to providing instructional materials which are applicable to the education of multi-handicapped children, as well as developing teacher training materials for teachers who are being prepared to meet the needs of this sub-group within the handicapped population.

Program Development Branch

The Program Development Branch is responsible for administering the child centered discretionary authorities within BEH (i.e., those authorities which provide direct funding to individual project applicants on a competitive basis). There are three programs within this Branch: Early Childhood Education, Deaf-Blind Centers, and Programs for Children with Learning Disabilities. A fourth program area, Child Advocacy Centers, will be discussed later.

1. Early Childhood Education Programs. The early Childhood Education program was authorized by Congress in 1969 to provide grants or contracts to public and private agencies to stimulate the development of comprehensive educational services for young handicapped children (0-8 years). The current budget of $7½ million is supporting 93 projects, including at least one project per state. Approximately 4,000 children are being served, of which approximately 35 percent are developmentally disabled.

Many projects involve retarded children, and frequently the multihandicapped retarded. One project is actually conducted in a state institution. The purpose of this particular project is to reduce the dependency of the children involved by maximizing their potential. This is being done by attempting to change specific behaviors in the children. There were 60 children in the original project whose ages ranged from early infancy to about eight. Most of the children are profoundly retarded and had been excluded from the educational and training programs within the institution. The results of this project have been very promising thus far. Most of the children are more independent than they were prior to the program, and many are now participating in the institution's regular education and training programs. Twenty-two of the children have left the institutional setting and are now being accommodated in local community programs. This program has changed the staff's expectations about the capabilities of the mentally retarded. There are similar projects around the country which are supported through other funding resources.

2. Deaf-Blind Programs. In 1968 Congress authorized funds for establishing comprehensive regional deaf-blind centers. Since the inception of the program, 10 regional centers have been established and are presently in operation. The current budget for this program is $7½ million.

Prior to the 1964-65 rubella epidemic, there were an estimated 600 deaf-blind children in the nation, and approximately 100 were enrolled in some type of formal educational program, usually in a private institution. Following the epidemic, the National Center for Disease Control estimated that there were nearly 4,000 such children. Surprisingly, but unfortunately, the Center's estimate proved to be low. The 10 Regional Centers have already located 4,700 such children. Of this number, approximately 1,300 are enrolled in educational programs, 700 are receiving diagnostic and evaluation services, 200 are receiving crisis care services, and nearly 3,000 parents are receiving counseling services. (NOTE: The Coordinator of the Bureau's Deaf-Blind program estimates that a minimum of 50 percent of all deaf-blind children would fit the developmental disabilities definition.)

At the present time, there are 92 educational programs in 46 States, which are supported by the 10 Regional Centers. For example, the Center for the Southeastern States, at Taladega, Alabama, has a contract (through the Federal grant) with the School for the Deaf and Blind at St. Augustine, Florida to support "tutor companions" for some of the "more able" deaf-blind students who remain in the State, rather than going to the facility at Taladega.

3. Learning Disabilities Program. Special programs for children with specific learning disabilities were authorized in 1970 under Part G of the Education of the Handicapped Act. Under this program, funds may be used to establish and operate model centers for the improvement of Education of learning disabled children. The funds also may be used for training special personnel and to support research and related activities.

Specific learning disabilities is a very difficult area to discuss in this context, because of the fantastically wide variance of opinion among professional personnel as to the nature and extent of the disability and the number of children who are included in this classification. Typically, the incidence rates which are used are 1-3 percent of the child population. However, it has been pointed out recently that the incidence rates more accurately fall between three and five percent of the child population (e.g., between 1,800,000 and 3 million children). It is estimated that about 20 percent of this population are brain injured, and would seemingly be eligible for services under the Developmental Disabilities definition.

The present funding level for this program is $2½ million. Twenty-three model-demonstration service projects are currently being supported, all of which are at the planning stage or early developmental level. These 23 grants have all been awarded on a competitive basis to state departments of education.

Aid to States Branch

The third Branch within the Division of Educational Services is the Aid to States Branch. This Branch is responsible for the administration of the state formula grant programs within the Bureau i.e., grants which go to state education agencies on the basis of a formula specified in the law. The states then award the funds to local education agencies, either on a competitive or entitlement basis, depending upon the specification in the individual legislative authority.

All four of the authorities in this Branch are child centered direct service programs. They are described as follows:

1. P.L. 89-313. The P.L. 89-313 amendment is Title I of the Elementary and Secondary Education Act of 1965 provides supplemental assistance to states to extend and improve the quality of educational services for children in state operated and state supported schools for the handicapped (including State residential schools for the deaf and blind and institutional programs for the mentally retarded).

There are very few restrictions on how these funds can be used. For example, they can be used to employ staff, or purchase equipment and materials, or to carry out almost any conceivable activity. But the central theme is always the provision of direct educational services and improved educational opportunity for individual handicapped children.

This is the largest program, fiscally, within the Bureau. The current budget is $56 million. Approximately 158,000 children are served by the P.L. 89-313 agencies and schools; and over 50 percent of the children served are mentally retarded. It is estimated that nearly two-thirds of all children in "31[illegible] programs fit the developmental disabilities definition.

P.L. 89-313 is a program which has really made a difference in the education of handicapped children. As limited as the funds are (in terms of overall costs for educating such children), they have made a difference between whether some children receive educational services or no program at all; and there are many children, previously considered to be hopeless crib cases who have responded to training and are making progress. There are a number of programs around the nation for older retarded children, which are achieving similar results to the preschool program mentioned earlier. American Forks, Utah, for example, has a very exciting program which has paid off year after year in raising the functional level of severely mentally retarded persons; and there are similar projects at Wheat Ridge in Colorado, Fairbault State Hospital in Minnesota, and so forth.

There has been a significant trend recently toward the de-centralization of the population served under P.L. 89-313. For example, in 1965-66, 98.7 percent of the children were in an institutional setting vs. 1.3 percent in some type of day program. Today, only 60 percent of the children are in institutions with 40 percent being served in some type of state operated community programs. Most of the older children apparently are moved to family or group homes or other community settings and receive their education and other services in small centers. This shift has real implications in terms of developmental disabilities activities, particularly in relation to the development of comprehensive, coordinated plans for serving the DD population.

*2. **Part B Programs.*** A companion program to P.L. 89-313 is Part B of the Education of the Handicapped Act (formerly Title VI of the Elementary and Secondary Education Act). The purpose of this program is to provide grants to states to initiate, expand and improve special education programs for handicapped children in local education agencies (i.e., the local school district is responsible for the education of these children, as opposed to the state itself, as is the case under P.L. 89-313).

This has traditionally been the foundation program within the Bureau, although the budget is relatively small (currently $37½ million, with an authorization of over $200 million). This program, like P.L. 89-313, also has had a real impact on the field of special education. In fact, it has had, overall, the most significant, far reaching effect of any Federal education program to date–particularly in terms of bringing visibility to the handicapped population. This visibility (which came about because of the planning efforts and the face to face contracts between state and local officials during the early days of the program) resulted in demands for service from local school superintendents and parents beyond that which would be normally expected.*

*3. **Set-Aside Programs.*** There are two other programs, which the Aid to States Branch does not administer directly; but the Branch does have a liaison, coordination role with the administering agencies. These two authorities are called set-aside programs, because a portion of the funds appropriated annually must be earmarked (set-aside) for programs and projects for handicapped children.

a. Vocational Education. Vocational Education is one of the set aside programs. The Vocational Education Act of 1968 specified that 10% of the funds annually appropriated under the Act must be earmarked for conducting career education programs for handicapped students. If the funds are not used for this purpose, they simply revert to the Treasury (they cannot be used for other purposes, or other types of programs). Approximately $38 million is available for such programs this year; and about 115,000 pupils will be served under this authority. Unfortunately, there are no specific data at this time on the types of handicapped children receiving these services; but it is quite clear that vocational education is potentially a very significant program for all handicapped children–including the developmentally disabled.

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*Because the funds are so limited in this program, most States have elected to make grants to local school districts on a competitive basis.

b. Title III, ESEA. Title III of the Elementary and Secondary Education Act is another set-aside program. The purpose of this funding authority is to provide grants to states to be used in supporting innovative and exemplary projects in elementary and secondary education–at the local school district level. It is essentially a risk money program, with the intent being to replicate any promising practices which result from the projects.

Under the law, 15 percent of the funds must be set aside for special projects for handicapped children. This currently amounts to about $20 million. Of approximately 200 projects for the handicapped recommended in 1971 by State Title III personnel as being exemplary, some 70 percent were projects in which developmentally disabled children could and did receive services. These projects ranged in scope from programs specifically designed for the neurologically impaired and rubella children, to diagnostic and prescriptive programs which served a range of handicapped.

The following are titles of some of the projects conducted under this program:

1. Family Learning Center for Children with Developmental Language Disorders
2. Communicating Classroom Management Techniques
3. Computerized Performance Adapted Resources in the Education of Handicapped Children
4. Guaranteed Performance Contract for Mentally Handicapped
5. Behavioral Engineering for Handicapped Children
6. Discovery Through Outdoor Education
7. Pre-sheltered Workshop and Community Placement Program

BEH OBJECTIVES

It seems appropriate at this point to present the major long-range objectives of the Bureau of Education for the Handicapped and to discuss some of the overall strategies used by the Bureau in carrying out its mission.

1. Primary Goal. First, it should be pointed out that the primary goal of the Bureau has always been to equalize educational opportunity for handicapped children so that each child will be able to achieve his fullest potential, and ultimately will be able to participate constructively in society to the maximum of his own abilities as an individual.

2. National Commitment. This, basically is a philosophical goal, which is generally acceptable to personnel in the education of handicapped children. However, in the Spring of 1971, Commissioner of Education, Dr. Sidney Marland brought this notion into the realm of reality. He publicly called for local state, and Federal education agencies to join together in making a national commitment to provide full educational opportunity for all handicapped children by 1980. This was quite a significant step, because it was the first time ever in the history of the Office of Education that special education was given such visibility.

*3. **Objectives.*** The following are the five major objectives of the Bureau:

(a) To assure that every handicapped child is receiving an appropriately designed education by 1980 (85 percent by 1978).

(b) To assure that by 1977 every handicapped student who leaves school has had career education training that is relevant to the job market, meaningful to his career, and utilizes his fullest potential.

(c) To secure the enrollment by 1978 of 850,000 preschool aged handicapped children in Federal, state, and local day activity programs.

(d) To assure that all schools serving handicapped children have sufficiently trained personnel who are competent in the skills required to aid each child in reaching his full potential.

(e) To enable severely handicapped children and youth to become as independent as possible, thereby reducing their requirements for institutional care and providing opportunity for self development.

*4. **Extent of Needs.*** The needs are evident, as indicated from the following, partial list:

(a) More than four million of the estimated seven million preschool and school aged handicapped children are still in need of special education services; and it is estimated that one million such children are totally excluded from school systems.

(b) Only 21 percent of the handicapped students leaving school in the next 4 years will be fully employed or in college. Forty percent will be under employed and 26 percent unemployed.

(c) There is a serious shortage of special education manpower. It is estimated that nearly ¼ million professional personnel are needed in order to meet the 1980 full services commitment. In addition, teachers currently in service will need additional training, in order to assure that handicapped students will be provided a quality education.

BEH STRATEGIES

In order to carry out the previously mentioned objectives, the Bureau of Education for the Handicapped has adopted two major strategies: (1) development of a catalytic role, and (2) adoption of a coordination and mutuality planning strategy. These two strategies, which are described below, transcend the individual programs which were described earlier in this paper.

Catalytic Role. In three of the five objectives cited earlier, the key action word, from the BEH vantage point, is the word ASSURE. The Federation government at this point in time is not in a position to assume major support for the education of handicapped children; and it is actually the junior partner in the Federal-state-local educational partnership.

Data from a recent study suggests that the cost of a quality education for all handicapped children would be approximately $5 billion. State and local education agencies are presently spending approximately $2 billion. It is clear that the present level of funding within the Bureau of Education for the Handicapped ($220 million, including set-aside funds) is such that a catalytic, seed money type of strategy is essential. This type of strategy is a basis for most of the BEH programs.

Dr. Sidney Marland in a speech made at the National Convention of the Council for Exceptional Children last year addressed the issue of catalytic funding. He pointed out that the Office of Education could set its goals in terms of just how far the Federal dollars go. For example, BEH could elect to use the $37½ million under Part B, EHA, to extend services to 20,000 more children. But through careful planning between state, local and Federal agencies, this amount could be used as a catalyst to stimulate better education programs for hundreds of thousands of children. The Bureau elected to follow the latter strategy. It is interesting to note that 90 percent of the Part B funds are used (1) as seed money to stimulate the development of basic programs for the handicapped (e.g., more special teachers, or speech clinicians), in which case programs started on Federal dollars are picked up on State and local funds, and (2) to carry out pilot-demonstration activities for various types of programs and services for which the States do not have enabling legislation.

An example of this type of catalytic-multiplier effect is seen in the revision of state laws to support new programs started with Federal funds. In California, for example, programs for multi-handicapped were previously not supportable on State funds. Five pilot projects were initiated with approximately $170,000 in Federal funds. These projects demonstrated to the State Legislature the efficacy of such programs, and the State law was amended to accommodate these children. In the first year of funding, $1.7 million was expended by the State for programs for the multi-handicapped. This represents a 10-fold increase over the amount of the original Federal investment.

Coordination and Mutuality of Planning Strategy

Coordination and mutuality of planning are clearly interrelated with the catalytic strategy. The Bureau of Education for the Handicapped is a small bureau in terms of dollars and number of staff; and it represents a minority group within the field of education. The Bureau learned very early in its existence that working together and coordinating with other agencies is essential if progress is going to be made in extending services to handicapped children. The first foray into coordination was directed at getting the OE "house in order." There are a whole host of OE funding authorities (including the four programs in the Bureau's Aid to States Branch previously mentioned, as well as the training authority in the Division of Training Programs) which have their own specific purposes, but which also can have tremendous overlap in the types of projects and activities which are conducted. For example, Part D, EHA is a training authority; yet there also is a training component in Part B, P.L. 89-313, Title III and Vocational Education. If there is coordinated planning within each state education agency, it might be possible to combine training efforts in a way which would be as efficient as carrying out separate training programs, and do so at a reduced cost.

BEH has been engaged for the last several years in carrying out a series of technical assistance conferences for state education agencies on coordinated, systematic planning in the education of handicapped children. The primary purpose of these conferences has been to attempt to bring about more effective use of the scarce resources available for the education of the handicapped, by reducing the fragmentation and duplication of effort which can exist, and thus maximizing the effectiveness of these funds.

When BEH talks about coordinated planning, at least in the context of the above programs, the term is used to mean (1) mutual, before-the-fact identification of major problems, objectives and strategies (involving all pertinent agencies), and (2) mutually pre-determining how the funds from each of the various programs can be used most effectively in meeting the objectives.

Work has also been underway in recent years with other agencies in HEW. The Child Advocacy programs are an excellent example of interagency cooperation. The National Institute of Mental Health, the Social Rehabilitation Service and BEH are jointly funding a series of child advocacy projects throughout the nation; and the three agencies have joint monitoring responsibility for these projects. This type of coordination, and these types of projects, will help insure that children in local communities will be guaranteed appropriate services, rather than being allowed to go unserved because of "institutional" conflicts as to which agency is responsible for the child.

DD Role

It should be clear that the above comments on coordination underscore the basic concept of the Developmental Disabilities legislation. The DD Act is really not a program operation authority, nor does it offer basic support for programs. Rather, it is a coordination authority. The bringing together of the nine agencies to engage in target group planning is as essential to the success of assuring appropriate, quality services for the DD population, as it is for BEH to engage in mutuality of planning with participating state and local agencies. The concept of a coordinating function is not only inherent in the Act itself, but the amount of funds available in most states is too limited to be effectively used for purposes other than planning, convening, and coordinating. Conversely, these three activities, when accomplished, will maximize the effectiveness of the scarce resources available from each of the participating agencies on behalf of DD children.

SOME ISSUES

The following are some of the pertinent issues related to the DD legislation, from the BEH standpoint. Most of these issues clearly underscore the need for coordination.

Multiplicity of State Plans

There are a whole host of State plans within HEW–one for nearly every program authority (including the DD Plan, itself, Title III, ESEA, Vocational Education, Part B, EHA, etc.). There must be a fantastic overlap in these plans, and the effectiveness of any one plan must be sharply reduced by such multiplicity. The number of plans should either be reduced, or provision should be made for showing within each plan the nature of its relationship with other program authorities.

Developing Meaningful Plans

It is clearly possible for the nine agencies involved in this legislation to feed in sufficient information to enable a State DD Coordinator to develop his State's Plan; and it is possible to comply with all of the other requirements of the Act; and yet never realize a real, valid, functional plan for serving developmentally disabled children. It is the observation of this writer that this is more the rule than the exception in most state plans, including many of the DD Plans. The process of planning together, before the fact, as well as on a continuing basis, is essential to the development (and implementation) of a successful plan.

In order to meet the real intent of the Act, people must be committed to the concept of coordinated planning—particularly those persons who are at the highest decision making levels within each State. But this kind of commitment will be made only when there is a firm belief on the part of the people involved that such mutuality of planning really pays off.

Developing Joint or Interlocking Agency Objectives

Some of the major governmental agencies have well defined, measurable objectives. For example, BEH has a full services objective with a time frame of 1980; the Secretary of HEW has a dependency reduction goal; and the President's Committee on Mental Retardation proposed a 50 percent reduction in mental retardation by the turn of the century. All of these are viable objectives. But if each were presented in isolation before a congressional committee or to an administration budget group, such presentations could raise questions in the minds of the committee members, and could result in a horrendous credibility gap. There is a need for an official acknowledgement of the interrelationship between all HEW objectives which are directed at the same target population; and, where possible, each agency's objective statements should acknowledge any obvious articulations of the objectives of other agencies.

Appendix A

Federal Programs Administered or Monitored by the Bureau of Education for the Handicapped, U.S. Office of Education Fiscal Year 1972 Appropriation

(Total – $227,291,116)

Type of Assistance	*Authorization*	*Purpose*	*Appropriation FY 1972*	*Who may apply*	*Where to get information*
Services					
Programs for the handicapped, preschool, elementary and secondary	Education of the Handicapped Act, P.L. 91-230, Part B	To strengthen educational and related services for handicapped, preschool, elementary and secondary children	$37,500,000	Local agencies apply to state departments of education	Division of Educational Services, Bureau of Education for the Handicapped
Programs for the handicapped in state supported schools	Elementary and Secondary Education Act, Title I (P.L. 89-313, Amended)	To strengthen education programs for children in state operated or supported schools for the handicapped	$56,380,000	Eligible state agencies apply to state departments of education	Division of Educational Services, Bureau of Education for the Handicapped
Title III, Supplementary education centers and services	Title III, Elementary and Secondary Education Act, as Amended	To provide grants for supplementary, innovative, or exemplary projects for the educational improvement of the handicapped	$16,438,116 represents 15% of state's total Title III allotment	Local education agencies apply to state departments of education	Division of Educational Services, Bureau of Education for the Handicapped; or Division of Plans and Supplementary Centers, Bureau of Elementary and Secondary Education
Early education for handicapped children	Education of the Handicapped Act, P.L. 91-230, Part C, Section 623	To develop model preschool and early education programs for handicapped children	$ 7,500,000	Public agencies and private nonprofit agencies	Division of Educational Services, Bureau of Education for the Handicapped

Appendix A (continued)

Type of Assistance	*Authorization*	*Purpose*	*Appropriation FY 1972*	*Who may apply*	*Where to get information*
Vocational education programs for the handicapped	Vocational Education Amendments of 1968	To provide vocational education and services to handicapped children	$39,273,000 represents 10% of the basic state allotment under Part B of the 1968 Amendment to the Voc. Ed. Act	Local educational agencies apply to state departments of education	Division of Vocational Technical Education, Bureau of Adult, Vocational and Technical Education Regional Office; or Division of Educational Services, Bureau of Education for the Handicapped
Media services and captioned film loan program	Education of the Handicapped Act, P.L. 91-230, Part F	A) To advance the handicapped through film and other media including a captioned film loan service for cultural and educational enrichment for the deaf	$ 6,000,000	State or local public agencies and schools, organizations, or groups which serve the handicapped, their parents, employers, or potential employers	Division of Educational Services, Bureau of Education for the Handicapped
		B) To contract for research in use of educational and training films and other educational media for the handicapped, and for their production and distribution	(Included above)	By invitation	Division of Educational Services, Bureau of Education for the Handicapped
		C) To contract for training programs in the use of educational media for the handicapped	(Included above)	Public or other non-profit institutions of higher education for teachers, trainees or other specialists	Division of Educational Services, Bureau of Education for the Handicapped
		D) To establish and operate a national center on educational media	(Included above)	Institutions of higher education	Division of Educational Services, Bureau of Education for the Handicapped

Appendix A (continued)

Type of Assistance	*Authorization*	*Purpose*	*Appropriation FY 1972*	*Who may apply*	*Where to get information*
Deaf-Blind centers	Education of the Handicapped Act, P.L. 91-230, Part C, Section 622	To develop centers and services for deaf-blind children and parents	$ 7,500,000	State education agencies, universities, medical centers, public or nonprofit agencies	Division of Educational Services, Bureau of Education for the Handicapped
Information and recruitment	Education of the Handicapped Act, P.L. 91-230, Part D, Section 633	To improve recruitment of educational personnel and dissemination of information on educational opportunities for the handicapped	$ 500,000	Public or nonprofit agencies, organizations, private agencies	Division of Educational Services, Bureau of Education for the Handicapped
Programs for Children with Specific Learning Disabilities	Education of the Handicapped Act, P.L. 91-230, Part G, Section 661	To provide for research, training of personnel and to establish and operate model centers for children with specific learning disabilities	$ 2,250,000	Institutions of higher education, state and local educational agencies and other public and nonprofit agencies	Division of Educational Services, Bureau of Education for the Handicapped
Research					
Regional resource centers for improvement of education for handicapped children	Education of the Handicapped Act, P.L. 91-230, Part C, Section 621	To develop centers for educational diagnosis and remediation of handicapped children	$ 3,550,000	Institutions of higher education and state education agencies, or combinations within particular regions	Division of Research, Bureau of Education for the Handicapped
Handicapped research and related activities	Education of the Handicapped Act, P.L. 91-230, Part E, Section 641	To promote new knowledge and developments with reference to the education of the handicapped	$15,455,000	State or local education agencies and private educational organizations or research organizational groups	Division of Research, Bureau of Education for the Handicapped

Appendix A (continued)

Type of Assistance	*Authorization*	*Purpose*	*Appropriation FY 1972*	*Who may apply*	*Where to get information*
Physical education and recreation for the handicapped	Education of the Handicapped Act, P.L. 91-230, Part E, Section 642	To do research in areas of physical education and recreation for handicapped children	$ 300,000	State or local education agencies, public or nonprofit private educational or research agencies and organizations	Division of Research, Bureau of Education for the Handicapped
Training					
Training personnel for the education of the handicapped	Education of the Handicapped Act, P.L. 91-230, Part D, Section 631, 632	To prepare and inform teachers and others who work in the education of the handicapped	$33,945,000	State education agencies, Institutions of higher education, and other appropriate nonprofit institutions or agencies	Division of Training Programs, Bureau of Education for the Handicapped
Training of physical educators and recreation personnel for handicapped children	Education of the Handicapped Act, P.L. 91-230, Part D, Section 634	To train personnel in physical education and recreation for the handicapped	$ 700,000	Institutions of higher education	Division of Training Programs, Bureau of Education for the Handicapped

(TOTAL – $227,291,116)

Part V
State Legislative and Administrative Action

Editor's Notes

Traditionally, state government has played a vital role in organizing, financing and delivering services to the developmentally disabled. The emerging recognition that society has a responsibility for caring for its least fortunate members has led to an expansion in the role of the public sector generally; at least in terms of the developmentally disabled, this growth in program responsibility has been most evident at the state level.

Enactment of the Developmental Disabilities legislation thrust upon state government a broad new mandate to plan, implement and coordinate federally funded services to the mentally retarded, cerebral palsied and epileptics. Therefore, it seemed important to designers of the November Conference that the viewpoints of state legislators and administrators be clearly articulated.

In his paper, Allen C. Jensen identifies the major trends in organizing and delivering state services, particularly in the human service area, and suggests some of the impacts these developments are likely to have on the DDSA program. Among the specific trends reviewed by the author are: (1) reorganizations which are leading toward the consolidation of human service programs into one or two agencies of state government; (2) creation of sub-state human service areas; (3) establishment of state planning or integrated planning and budgeting agencies in the Governor's office; (4) a rise in "consumerism" and a resultant proliferation of advisory boards and councils; (5) increased state legislative staff; and (6) growth in the involvement of elected state officials in federal-state relations.

Ernest Dean discusses the implications of the Developmental Disabilities Act from the perspective of a state legislator who has long advocated expanded state services for the developmentally disabled and other handicapped citizens. He reviews the functions of state legislatures and discusses the results of an informal survey he conducted among key legislators in selected states to ascertain their views on the status of the DDSA program. Dean also outlines his philosophy on the role of state government in serving the developmentally disabled and closes with a few cautions, suggestions and recommendations to members of state DDSA councils.

Dynamics of Change in State Government—Impact Upon The Developmentally Disabled

Allen C. Jensen

Most of the participants in this conference are, because of the primary role of States in administering the federal grant-in-aid Developmental Disabilities Program, aware of the changes in state government of their own respective state. A primary purpose of this paper, therefore, is to attempt to identify the dominant themes of these changes in all the States so as to assess their collective impact on policy development and planning and the administration of programs for the developmentally disabled. This is, of course, a difficult task. While it is often easy to assess the actual structural changes we see taking place in state government and the changes in decision-making processes; to assess the actual impact on a particular client group such as the developmentally disabled becomes rather difficult.

Such an effort must recognize wide variations between States; not only variations as to the nature of changes such as consolidation of human service agencies, increased emphasis on cross program planning, or increased staffing for state legislatures, but also the stage or phase of such changes. Phases range from early planning, to early implementation, to reevaluation of earlier changes in order to determine further modifications of structure or process for administering human services programs. The following are the changes in state government which will be discussed in this paper:

A. Reorganization of state governments to consolidate into one or two departments a large number of human services programs.

B. Establishment by executive order or state legislation of common sub-state services areas for state human services programs.

C. Establishment of a Governors' state planning or integrated planning and budget office and/or establishment of planning and budgeting divisions in consolidated state human services agencies.

D. Consumerism and manageable administrative structures–the dilemma.

E. Increases in state legislative staff.

F. Increases in state elected officials involvement in federal-state relations.

REORGANIZATION FOR CONSOLIDATION

A dominant theme of state government changes in the past five or so years has been the reorganization of state government. A number of separate human service programs have been consolidated into large departments called Human Resources Departments, Health and Welfare Departments of Health and Social Services or a similar name.

The major consolidation trend at this point places welfare social services, which are now a 2½ billion dollar federal program, in the same department with the mental health and mental retardation service agencies. Twenty-four states have done this. Twenty states have the welfare social services program and the public health program in the same department. Fifteen states put welfare social services in the same department with mental health, mental retardation, and vocational rehabilitation. While at this point in time probably half the states have the vocational rehabilitation program in the education department, there is a strong trend to place it in social services departments.

There are 19 states that have 10 or more services (such as those for mental health, mentally retarded, corrections, employment, welfare social services, public health) in a consolidated department of human resources. There are 28 states in which seven or more of the programs related to the Developmental Disabilities Act and required to be included under the state plan are in one consolidated agency.

These agencies are organized in various ways. Some are organized according to their primary functions such as operations, technical assistance, planning and evaluation and management services. Others are organized by program such as public health, mental health, employment service, welfare, etc.

In public administration terms the reasons for such action include:

1. To reduce the number of individual agencies reporting directly to the Governor thereby increasing the Governor's ability to coordinate and administer human service programs.
2. To give authority for coordinating a broad range of human service programs to a single agency administrator or administrators.
3. To improve managerial systems and/or capabilities of the state in respect to the delivery of human services.

It is recognized that if the objectives in administering human services programs are stated predominately in terms of efficiency, cost-benefits and economies, fear and skepticism is felt by some. They feel significant service goals include attempting to achieve greater human dignity; where benefits may be measured in terms of self care, not always self support; and where the need for individualized services may run counter to attempts to achieve economy and efficiency by group services.

Many of the programs and services needed by those with developmental disabilities are included in such consolidated human services program departments. A recent analysis of consolidation considered those federally aided programs administered by States which are to be included in the cross-program planning element of a state plan under the Developmental Disabilities Program. About half of the States had 70 percent or more of those programs administered by one consolidated human resources department.

Many of these consolidated departments are in their first stages of development. In a number of States a Secretary of Human Resources (or some similar title) is appointed. His responsibility during the transition period is to develop a recommended administrative structure for the department for consideration by the Governor and legislature. The form and lines of authority for the consolidated human services departments will be better known following the transition period.

It is, quite frankly, too early to tell what the total impact of these consolidated human services departments will be on services to the developmentally disabled.

Form and structure of state government are important as potential tools. However, the use of such tools as relates to a particular client group will depend on several variables. Among these variables are: (1) the size and scope of the department in which the various service programs are located, and (2) the location in such department of the specific federally funded program for those with developmental disabilities.

State elected officials are, like federal officials, often confronted with competing demands, i.e., for establishing major visibility, for coordination power, or for high level advocacy positions in state government to represent various groups of people needing governmental services, including not only the developmentally disabled, but the aged, children, the mentally ill, etc.

It must also be recognized that there is the necessity for interagency planning and programming for particular services such as health, social services, food and nutrition programs, manpower programs, and child development services, etc.

It should be noted that the specific agency or advisory council for the developmentally disabled is not the only place in state government where the various roles and functions (advocacy, planning, coordination, and the power to allocate resources for services to the developmentally disabled) take place.

SUB-STATE SERVICE AREAS

Another trend has been the establishment, by executive order to state legislation, of common sub-state service areas for state human services programs.

Over 40 states have created *common* sub-state planning and service areas which are to be used by agencies and organizations in state government for planning and administering programs. This effort is in various stages of development from the initial designation of such areas to more highly organized sub-state service districts with major involvement by local government.

The purposes of such actions include:

1. To provide a common population base for determining needs of the individuals in an area for a number of interrelated human service programs.
2. To provide a common geographic service area which facilitates and simplifies communication between human service agency personnel.

3. To allow the use of the same field office accommodations and some general services personnel by more than one agency.

4. To provide opportunity for greater involvement by local governments in the planning and provision of human services and to reflect the local priorities and situations.

It is recognized that some services (for example, a neighborhood center as contrasted to a vocational training center) may require varied sizes of population groupings and geographic areas. However, sub-area designation for certain kinds of services does not mean that the basic concept of common sub-state service areas is negated. This type of effort certainly is one that should be supported. Those concerned with the developmentally disabled should be helping the states make systems *workable.*

I remember that about seven years ago in the state where I worked the employment service thought that sub-state regions were a tremendous idea. They decided to concentrate most of their services in the small city that was located in the middle of a sub-state service area having a 50 mile radius. It was a misuse of the concept of sub-state service areas because many of the people they were trying to serve with the intensive services didn't have transportation. In many cases, there need to be and are being established satellite centers and outreach programs to take the services to the people. These are complementary to the central office intensive service capabilities.

The following is a brief description by the state planning office in Georgia of the plans being made to utilize sub-state areas as the merging point for various human services and as a logical extension of the consolidation of all human service programs.

> "The most significant health related initiative taken by Georgia during the past year has been the consolidation of all human services programs into a single State agency. The objective of this consolidation is to create a single force in government which will efficiently deliver comprehensive programs and services for the physical, mental, and social well-being of Georgia's citizens. As a logical extension of this effort we are beginning to merge services at the point of delivery. Human development services in Georgia will be administered at the substate level through Human Resources Districts. For actual delivery of services, each district will be subdivided into Area Service Networks with a population base of approximately 200,000.
>
> The Area Service Network will comprise a Headquarters Unit, staffed by a director, special mental health personnel, and professionals, paraprofessionals, and general staff related to the full range of human development services. The Network will provide assessment and diagnosis services, counseling, protective services, foster care administration, etc. Initially, two Health Access Stations will be developed for each Network, to serve secondary population centers in each district. All day care centers for the aged, pre-schoolers, mentally retarded, etc., as well as group homes for the disturbed, though not co-located, will be attached administratively to the Area Network Headquarters Unit.
>
> At the county level, Human Resources local offices will make extensive use of paraprofessionals for outreach and

extension services, providing referral to professional assistance as needed and bringing a new perspective to case management."

PLANNING AND BUDGETING

Still another trend has been establishment of a Governor's state planning or integrated planning and budget office and/or establishment of planning and budgeting divisions in consolidated state human services agencies. Among the purposes of such actions in state government are:

1. To relate budget requests to the Governor's program priorities and goals.
2. To interrelate program and budget requests from the various department administrators with related service functions.
3. To facilitate the definition of responsibility among agencies in the department and between departments and possible shifting of specific responsibilities provided by separate service agencies in the agencies and departments.

Once again with the broad array of services and programs which are needed by the developmentally disabled and which are required to at least be coordinated on paper in the state plan for the developmentally disabled, the question must be asked whether or not the federal program requirements are complementary to what some states are attempting to do through integrated planning and budgeting systems which cross a number of program lines.

CONSUMERISM AND MANAGEABLE ADMINISTRATIVE STRUCTURES – THE DILEMMA

Perhaps it is useful to point out that one of the major dilemmas is that as we develop more sophisticated administrative mechanisms and structures for delivering services, there is a rise in what is called "consumerism" and increasing federal requirements for advisory or policy making councils for particular services or programs. This may conflict with efforts to consolidate agencies and provide administrative means for coordination, etc. of a broad range of human services. Achieving a balance between "consumerism" (citizen and client group participation in the planning and policy making process) and manageable administrative structures with sufficient centralization of authority is one of the most difficult problems facing those organizing and developing consolidated agencies.

INCREASES IN STATE LEGISLATIVE STAFF

Another major change in state government which perhaps has one of the most significant impacts on services for the developmentally disabled is the major increase in the size and specialization of the staff for state legislatures. Many state legislatures are now developing staffs which have specialization for dealing with the handicapped, or welfare, or education. Such staff offers state legislators independent information and program analysis sources and increases their ability to establish priorities and affect the means of delivering services for the developmentally disabled.

INCREASED INVOLVEMENT OF STATE ELECTED OFFICIALS IN FEDERAL-STATE RELATIONS

The office of Federal-State Relations of the Council of State Governments in Washington, D.C. was established in 1967. Since that time Governors, legislators, budget officials, planners, and other state officials have received more direct information about federal legislative and administrative actions. There have also been major increases in the opportunities for direct interaction with the Congress and federal executive branch officials by state elected officials and their staffs. Such interaction has permitted states to express their views on various proposals to create or modify federal grant-in-aid programs.

Perhaps some of the most significant efforts to involve state officials in federal-state relations will be held in December 1972 and January 1973. A conference for state budget officers and two conferences for state legislators and their staffs will be held during this period. Requirements and options available to states under the revised social services program authorized in the Social Security Act, and the revised welfare program for the aged, blind and disabled will be discussed with the state officials attending the conferences. These programs will have a significant impact on the developmentally disabled.

Last May The Council of State Governments convened for the first time with about a dozen directors of state consolidated human resources agencies. The ad hoc one day conference provided these officials with an opportunity to exchange ideas as to goals, primary accomplishments, and chief problems they have confronted. They visited with HEW Secretary Elliot Richardson regarding the interrelationship between state consolidated human services departments and his efforts to: (1) be more responsive to these kinds of changes in state government, and (2) provide additional tools to States to improve the administration and integration of human services.

At that particular meeting there were some comments by the human resources department directors which summarize some of the things discussed in this paper. Here are three comments which I think are pertinent.

1. The goals of reorganization won't be accomplished until the services are put together at the local level.

2. Problems arise because of public expectation that major savings will result from reorganization. In fact, increased accessability and needs assessment capability may so increase demands for services that it offsets any savings resulting from reorganization.

3. Accommodation must be made for the changes of roles of the state statutory boards and commissions (which often have very prestigious people sitting on them).

This list of changes in state government is not exhaustive but perhaps it gives some indication of trends which will have an impact on the developmentally disabled.

Two brief papers by directors of the state consolidated human resources departments in Arkansas and Florida which describe the structure, goals, and current activities of their respective departments follow in Appendices A and B.

COMMENTS AND IDEAS FROM RESOURCE PERSONS

Al Marshal

One danger of burying the program for the mentally retarded in a larger human resources department is dilution of the clout of those advocates for a specific client group such as the developmentally disabled. For example, you are forced to make your pitch at a lower level to a deputy commissioner–who makes his pitch to a commissioner–who has 17 deputy commissioners–each of whom has "his own bag." Then the commissioner tries to relate these requests and establish priorities before speaking to the governor. On the other hand, when you have the State Association for Retarded Children "coming down like a ton of bricks" on a commissioner for mental retardation who has to speak directly to the governor, he often speaks with more fervor, more excitement, more concern because "he knows he has those hungry ones out there after him."

The advocates of services for the developmentally disabled were cautioned not to let pursuit of "coordination" result in giving up some aspect of effectiveness in the advocacy role.

Do not fail to distinguish between the mechanism or vehicle which can most effectively provide a *service* and the functions of integrated *planning* for various kinds of governmental services. This is one reason many states have established a state planning agency or planning coordination agency separate from the agencies responsible for delivering services.

Concern was expressed that in some of the larger states, if all of the various elements are thrown together to come up with a department of human services, you may create a very useless animal. The department could be so large that it could not possibly deliver the day to day services.

Doris Fraser

Listed three points about change in American society:

1. The U.S. has an open-ended society that is able to change, going to change, and a Constitution that allows us legally to change.
2. Americans have the ability to look ahead and be open-minded about the fact that we are able to change.
3. This places a tremendous amount of responsibility on the citizen, the consumer, and the person advocating for change.

In another conference discussion someone said, "Don't worry about the fact that the consumers on your State Developmental Disabilities Council don't know anything about the federal laws or State plans submitted to the federal government. Just let them ask the experts. They'll tell them all about it." My response to that is, "The extent to which your family and my family know where the decisions are made, who is responsible, and who to contact to get things done, plays an important part of the total scheme of government." This knowledge is also related to the degree of alienation of the people from federal, state and local government.

An instrument in state government that can affect resource allocation is needed in order to really affect the various state programs and federal grant-in-aid plans which affect the developmentally disabled.

[NOTE: Her comments are based on her experience since 1967 in the Office of Planning in Massachusetts where a team was responsible for developing the plans for the modernization of state government. That planning resulted in a coherent form of government where there had previously been 172 departments and 323 boards and commissions. The Bureau of Developmental Disabilities which she directs is now in the Executive Office of Administration and Finance because it was felt that it was important to set a priority for a vulnerable part of the population called the mentally retarded.]

A lot of the rhetoric about the need for increased efficiency and effectiveness in government is political. It is based on the tremendous pressure caused by insufficient revenue to meet the competing demands for services and by many politicians' unwillingness to state what the nature of tax reform should be.

Integration of services must be a "bottom up" as well as "top down" affair. Some of the most sophisticated human services planning for reorganization is reorganizing the service delivery system itself, at the bottom.

Local service delivery reorganization should include case management centers.

In the past, service delivery has combined two important functions. The person responsible for delivering services has been (1) the manager of the client and (2) he was the provider of services to that client as well. I believe that is wrong because it prevents the opportunity for clear cut evaluation. The service provider is not in a position to evaluate the services he gives. That task belongs to someone else.

In our society with its complex functions there needs to be a person to manage the services and the person(s) in the services. His whole job is the responsibility of seeing that this person or family is managed through the system. His job is different from that of the service provider. He becomes an advocate who is protecting the client in making sure that the system is adequately planning for and meeting service needs (number of days in treatment, day care, in institution, checking back to see whether the treatment is effective).

Another element in service delivery is consumer representation. In many of the laws being passed you will find new processes being built into public services; appeal mechanisms and review mechanisms are being built in. With the aid of federal regulations in Title 19 there is going to be annual review, periodic review, etc. These are very crucial things where any kind of human services legislation is up for consideration. Citizens must have a built-in system of appeal.

WORKSHOP DISCUSSION

Will many more states consolidate human resources departments or will there be a breaking off?

Jensen:

That's difficult to generalize because there's an extreme degree of variation. Some governors can live with the situation where they have a large number of people reporting to them. Some governors want information in greater depth. Also, the sheer size of a state like New York may mean that what works in Delaware wouldn't work in New York. There isn't a single appropriate way to do it for each and every state.

Who sets the priorities for determining who receives services?

Fraser:

The question in Massachusetts right now is basically how much authority do you give the sub-state area administrator.

A main inefficiency of our government is the failure to make program managers of our program servicers. Regional administrators must have some flexibility in their own budgets to be able to deal with regional differences such as increased pressure for a particular service in any given fiscal period (for example, training versus counselors). They need an account through which they can respond to the unmet needs of a particular service area. Of course there must be certain basic eligibility conditions set as there are now. If you go to a stronger and stronger vendor payment program, then of course you are into the rate setting approach as opposed to the public institution approach.

A rising pressure for change is the request for community based programs for people who have by and large been in the institutions. Now consumers are saying this is no longer adequate and that institutions are inefficient from every point of view. They want a vendor payment program utilizing a full mix of proprietary, non-profit, and diversified sponsorship to produce continuity of care.

Most of those delivering or administering services, including those running the big public institutions for the mentally retarded, have the right objective but the machinery isn't in place yet. I think it will take the next 10 years to get into the vendor approach to the care of the severely disabled.

It is well agreed that there is the need for resource reallocation—i.e.. shifting resources from institutional care to community based care. However, there will be problems related to the displacement of the work force in institutions, with resulting pressure on legislators from those workers. In the power struggle we're going to need a new breed of managers whom the legislators trust and respect.

Where did the impetus for state reorganization originate?

Jensen:

There are three possible reasons for reorganization:

1. Frustration—150-200 state agencies and no way governors' staff could relate to that many agencies.

2. Efficiency—centralization of some of the administrative functions.

3. Reduce fragmentation—improve effectiveness of programs by consolidating related agencies in such a way that coordination at the operating level will serve to strengthen all programs so combined.

Marshal:

Part of the impetus for reorganization in states is even more basic. For many years the federal government played a minor role until the 1930's. Most direct services and many indirect services were performed by local governments. During those years the state governments were the most ineffective level of government because they were not expected or called upon to perform a lot of services.

Then came the need for state government to become an effective operating government. As the federal government began to participate with funds and with standards and guidelines, a vehicle was needed that could be effective within the power units that already existed, namely the state governments. There came about an emergency recognition that some of the problems to be solved, the new levels needed, and the new roles that we wanted government to play, could no longer be handled by one local government.

The emergence of the nation had caused local governments to start to lose some of their efficiency. At the same time, in order to be efficient we needed a level of government below that of the federal government. While political scientists promoted regional government, obvious political reasons dictated a try at making state government become an effective government.

The great American traditions of efficiency and economy were natural (additional) incentives.

In the last 15 years, every piece of federal legislation that I know of has in one way or another strengthened the role of state government. It's been an evolutionary process.

How do you accomplish state reorganization and at the same time get the information down to the local level about what is going on at the state level?

Marshal:

The workers in the vineyard know about it and they know about it soon!

To develop a strong central form of government, the best way is to get all the people who can to participate in the development of and acceptance of the plan. Then eventually, a point is reached where some people just do not want to accept the new look. Those people must leave.

The worst possible technique is to go the opposite route and leave field people out of the development process. If the field people don't want the clients to know what the reorganization is about; or if they want to distort it because they don't buy the idea, weren't consulted about it, don't like it, or some other reason; you're dealing not only with a man of ignorance but also with an outright attempt by your staff to destroy the plan, to misinform and mislead people.

In our reorganization efforts we've always made it one responsibility of the new entity to reach out and spread the gospel of the new look. No one else can do that successfully because anyone else appears as an outsider.

Fraser:

In Massachusetts the state staff spent a great deal of time at meetings of the

Massachusetts Association of Retarded Children orienting them to the political possibilities that this reorganization has for them.

We must have people in government who are willing to go out and converse with the consumer on his terms. Unfortunately, not many in government can do this comfortably; by and large they're quite defensive.

Jensen:

Some states include dissemination of information between levels as one of the functions of the sub-state area directors.

A comment was made about state legislative involvement and checks and balances.

Dale Engstrom

We've been talking about government agency ties at the state level but don't forget the legislative branch. In the last 10 years there's been a great change in the calibre of state legislators. Those knowledgeable people who are willing to take initiative provide more of a check and balance between the legislative and executive branches of state government than we've had in the past.

New roles of citizens were stressed.

Fraser:

We need to note the role in which citizens are increasingly taking on more and more authority. We see new types of boards and commissions emerging. Those with monitoring, policing and program policy formulation attributes drop down to sub-state jurisdictional levels. That's okay. We don't want to consolidate everything. We need vehicles for people to be involved. People have to identify with policy formation. These are tremendous learning processes.

Even if the Kennedy mental health system did nothing else, it did involve citizens in a new kind of way. I don't think you'll see citizens giving up any of the power they gained in those reorganizations of the past 10 years. Once they taste involvement they don't want to give it up.

One of the greatest challenges of reorganization, then, is examining under what conditions citizens will participate. There is a widely held notion that the executive branches of government have become so powerful that the citizen has no opportunity to participate in shaping his own destiny. Many policies and procedures are set down with no chance of appeal. When even the middle and upper middle classes lack the time and appetite for the battle, the poor citizen is helpless. Therefore, citizen participation in determining conditions for citizen involvement is especially important.

Appendix A

STATE OF FLORIDA

DEPARTMENT OF HEALTH AND REHABILITATIVE SERVICES

BACKGROUND

Prior to July 1, 1969, Florida's executive branch of state government was an unwieldy and unresponsive structure composed of more than 220 separate independent administrative agencies. In the spring of 1967, a newly reapportioned state legislature met and drafted a new constitution for Florida. This new Constitution included a provision which required that all of the executive agencies of Florida would be reorganized into not more than 25 administrative departments prior to July 1, 1969. From this Constitutional mandate for reorganization grew Florida's new Department of Health and Rehabilitative Services.

Prior to reorganization, there existed 15 independent agencies working in an area described as human resources or social and health services. These agencies were as follows:

Division of Corrections
Division of Youth Services (Youth Corrections)
Division of Mental Health (Institutions and Community Programs)
Division of Mental Retardation
Division of Vocational Rehabilitation
Florida Council for the Blind
Commission on Aging
Crippled Children's Commission
State Department of Public Welfare (Public Assistance and Medicaid)
Division of Community Hospitals and Medical Facilities
State Board of Health (Including County Health Departments)
State Tuberculosis Board
Pest Control Commission
Comprehensive Health Planning
Alcoholic Rehabilitation Program

The above agencies together include 37% of all state employees and an annual budget of over $600,000,000. They were administered by various committees composed of members of an elected cabinet or independent boards and commissions appointed by the Governor. This semi-independent, multiheaded administration resulted in a system which was unresponsive to policy direction from the Governor or the legislature and which did not have a clearly defined administrative authority which could be held accountable for the action or inaction of the agency.

Recent advancements in computer and management information systems and comprehensive planning provide the technology for developing a more efficient means of delivering social services. Florida's previous structure of multiple, independent social service agencies did not provide the organizational base necessary to take advantage of modern management tools. Consequently, a comprehensive department was created under the authority of a single secretary appointed by the Governor. This new Department of Health and Rehabilitative Services combined the above 15 agencies into nine divisions including:

Adult Corrections
Youth Services
Mental Health
Retardation
Vocational Rehabilitation

Family Services
Health
Administrative Services
Planning and Evaluation

The new Department of Health and Rehabilitative Services includes most of those agencies which, prior to reorganization, were making an uncoordinated, duplicative effort to deal with problems of Floridians.

The need for coordination of social services is emphasized by the trend to develop community-based service programs and to provide service to families rather than service to individuals. For example, correctional work release centers, rehabilitative facilities, youth halfway houses, community mental health centers and public health clinics are developing at an increasing rate. Each agency feels that it is uniquely qualified to treat the family. Since most disadvantaged families suffer from several disabilities, the overlap of services and facilities is significant in terms of cost effectiveness of the tax dollar spent.

In order to effect administrative accountability, the reorganization of Florida health and rehabilitative services included the abolishment of all state boards and commissions, as well as local boards and commissions involved in administrative or quasi-administrative activities. This resulted in vesting all the power and responsibility for administration of all social service agencies in a single secretary appointed by the Governor.

The creation of the new Department of Health and Rehabilitative Services established the framework from which could develop a more effective and efficient means to deliver health and rehabilitative services in Florida. The Department has moved in the direction it appeared the Legislature intended

A central computer-based information system, utilizing remote video communications, has been developed for public assistance payments management and Medicaid prior authorization and control. This system is being expanded into a single integrated departmental information system.

A uniform system of 11 departmental regions has been developed and all program operations have been realigned within the new regional structure. Three experimental departmental administrators have been assigned responsibility for coordinating and administering three of the regions. Departmental staff Divisions of Administrative Services and Planning and Evaluation are developing a comprehensive program planning budgeting system which to date has provided the management framework by which Florida has increased its federal funds under Titles IV-A and XVI of the Social Security Act.

Within one experimental HRS region all services are being developed and coordinated through single comprehensive service centers. Service centers are under a single director responsible to the departmental regional administrator with authority over all program/service components. Uniform application forms and central case management are being developed within the local service centers.

A system of accountability for client progress toward self-sufficiency (if possible) is being implemented within two regions on an experimental basis. The system includes identification of community and individual needs, available resources, cost of present services and projected costs to meet unmet needs. This is an experimental effort to develop appropriate accountability within the entire health and rehabilitative services system. This includes holding the service system accountable for client progress at the point where the services are delivered, as well as holding the Governor and the Legislature accountable for allocating sufficient resources to meet identified service needs within the state.

Appendix B

ARKANSAS

DEPARTMENT OF SOCIAL AND REHABILITATIVE SERVICES

In 1968, the Chairman of the Department of Political Science of the University of Arkansas presented a plan for reorganization of State Government in Arkansas to former Governor Winthrop Rockefeller. In January, 1971, Governor Dale Bumpers adopted a modification of this plan and presented it to the 1971 General Assembly. The plan was passed as Act 38 of 1971. The language of the Act gives some indication of the goals of reorganization. The stated legislative purposes were to create a structure of state government which would be responsive to the needs of the people of the state and sufficiently flexible to meet changing conditions; to establish executive authority over those areas where executive responsibility existed; to provide a reasonable opportunity to create budgetary and administrative efficiency within an orderly organizational structure of state government; to strengthen the role of the General Assembly in state government; to encourage greater participation of the public in state government; to effect the grouping of state agencies into a limited number of departments primarily according to function and to eliminate overlapping and duplication of effort.

The objectives of the reorganization as stated in the original plan are: (1) It attempts to reduce the fragmentation amounting almost to chaos in the present administrative organization by combining the multitude of agencies into 13 principal departments; (2) It attempts to improve the effectiveness of programs by consolidating related agencies in such a way that coordination at the operating level will serve to strengthen all programs so combined; (3) It attempts to go as far as administrative machinery can go toward insuring that the most effective and efficient use will be made of the state's resources.

The recommendation for a Department of Human Services was, in the wording of the report, "to attempt to combine in one department a number of agencies which have programs directed at persons who by virtue of age, economic status or other factors, are marginal participants in the social process." Although not specifically stated as a goal, there was an implication that service programs would be more effective at the community level and that more federal funds would be available under a system of coordinated service delivery. Both predictions, incidentally, have been amply justified.

We have provided an organization chart of State Government in Arkansas which shows the Department of Social and Rehabilitative Services, which is a department of human services, in relation to the other components of the executive branch. In addition, we have provided an organization chart which shows the divisions of the Department of Social and Rehabilitative Services. There are six divisions, in addition to those units that are attached directly to the Office of the Director.

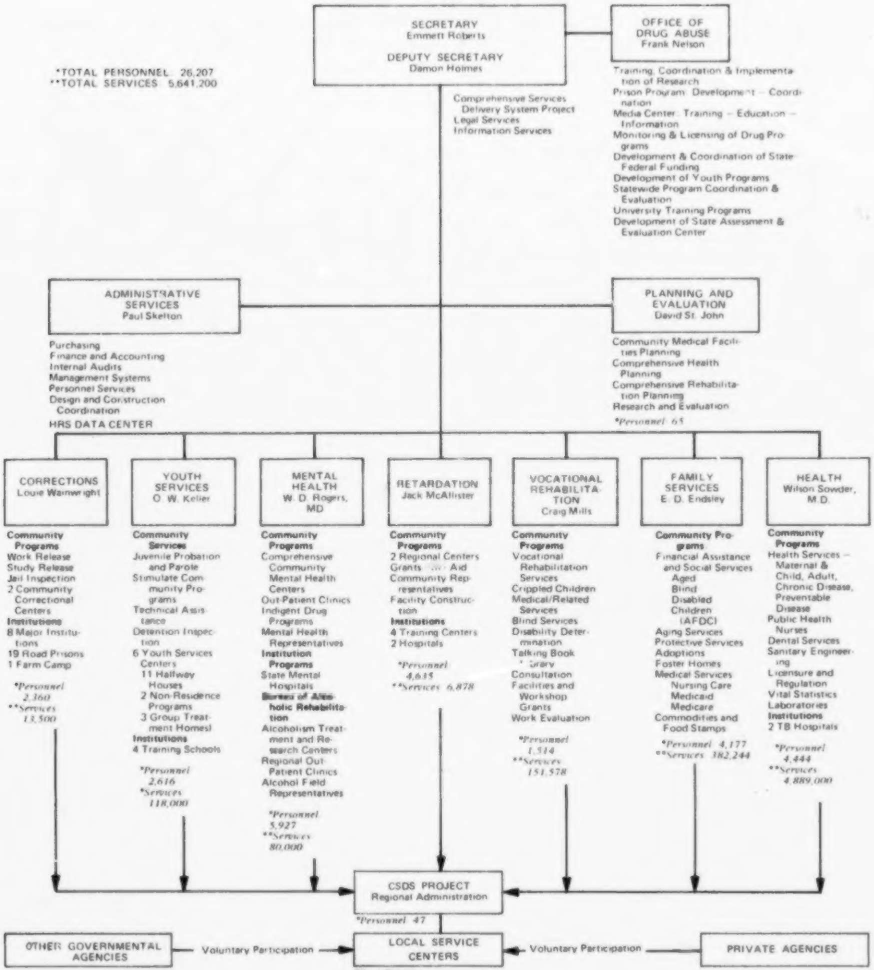
The divisions are: Mental Health Services, which includes the State Mental Hospitals and Community Mental Health Services; Juvenile Services, which includes the State Training Schools for Juveniles and a newly created Community Services Division, Workmen's Compensation Commission, which frankly should not have been placed in a Department primarily devoted to services; Mental Retardation-Developmental Disabilities Services, which includes the Arkansas Children's Colonies and a Division of Community Services; Rehabilitation Services, which includes the Rehabilitation Service Programs for the Blind, the handicapped and the disadvantaged; the Commission on Alcoholism; the State Kidney Disease Commission, and the Arkansas Rehabilitation Research and Training Center. Finally, the Social Services Division which was formerly the Department of Public Welfare. It includes the traditional welfare, social and medical programs, as well as the Office On Aging.

Four programs relating to education and early childhood development were transferred to the Department and have been combined into the Early Childhood Development Program which is attached directly to the Office of the Director. It is likely that we will eventually create a new division which will include small programs such as Early Childhood Development Program, the Office On Aging, the new Alcoholism Program, under the Hughes Legislation, and possibly other programs of a similar nature including those which provide consultation and technical assistance to communities.

It is difficult to single out two accomplishments of the Department during the first year of operation. There have been many significant accomplishments and they are interrelated. For example, one major thrust of the Department has been to increase the quantity, quality, and responsiveness of services at the delivery level. In order to bring this about, we have used state appropriated funds from the Community Mental Health Division, Juvenile Services Division, Mental Retardation Division and Rehabilitation Services Division to match funds from Titles IV-A and XVI available to the Social Services Division, and thereby increase funding of programs threefold. Because of the scope of this increase it was necessary to call the Legislature into special session to give the Department additional spending authority in order to handle the new state and federal funds passing through the Social Services Division. A second accomplishment which is related to this is the department's regionalization program with the creation of eight service regions covering the state. In the future all planning and supervision of our human services programs, particularly at community level, will be regionalized with the hope that they will be better coordinated and more responsive to the needs of the individual being served. We are anticipating a grant award for an Integrated Services Project from the Office of the Secretary to carry out a demonstration project in one of the regions of the state. It is probable that we will be able to fund a position of coordinator in the remaining seven regions with funds saved through a Department-wide Public Service Careers Project for approximately one million dollars.

Predictions that the Commissioners over the various agencies in the new department, who formerly reported only to the Governor, would not be cooperative, and would not work for the betterment of the department were wrong. The Commissioners have responded in a professional manner and have given full support to the Departmental concept. Each agency has benefited in significant ways from reorganization due to increases in funding and through new support services from the Office of the Director, and from the various project grants that have been awarded to the Department as a result of reorganization. We estimate that the financial benefits of reorganization have been at least 20 times as much as the costs involved in setting up the Director's office. These will be continuing benefits that should become even greater benefits during the coming years.

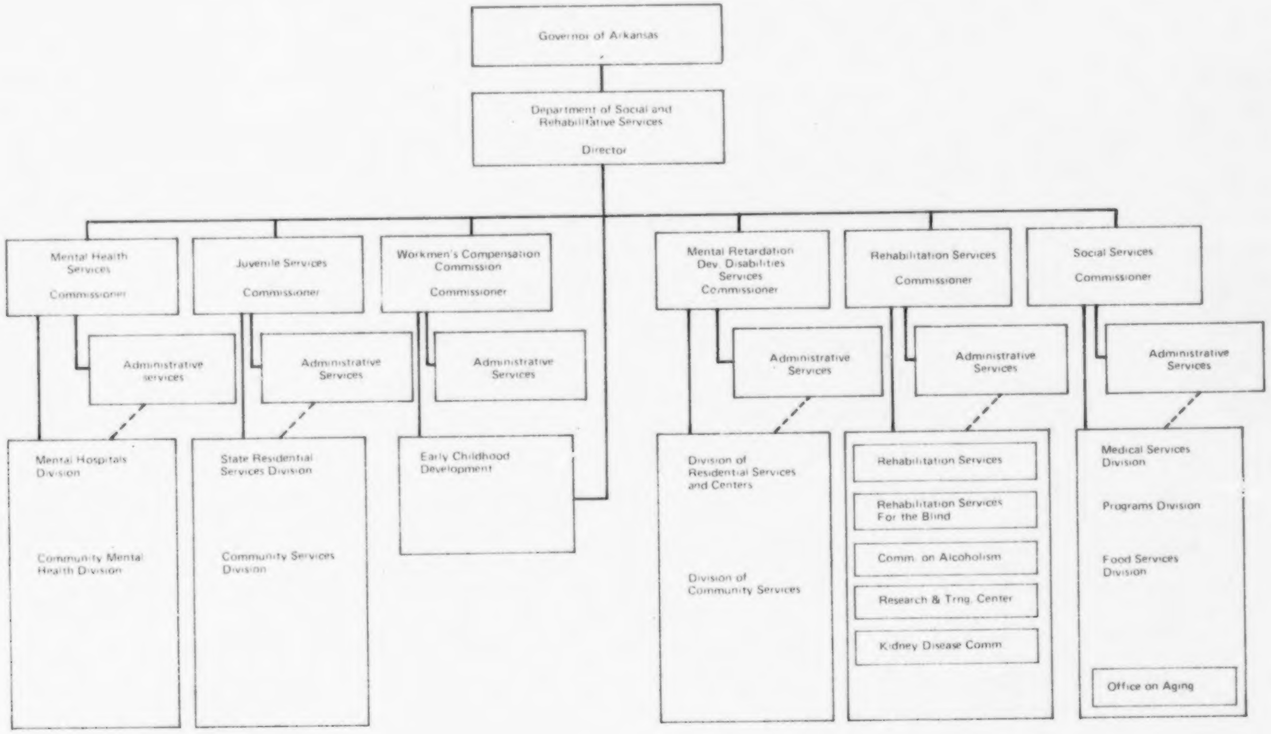
DEPARTMENT OF HEALTH AND REHABILITATIVE SERVICES


*TOTAL PERSONNEL 26,207
**TOTAL SERVICES 5,641,200
SECRETARY
Emmett Roberts
DEPUTY SECRETARY
Damon Holmes
Comprehensive Services Delivery System Project
Legal Services
Information Services
OFFICE OF DRUG ABUSE
Frank Nelson
Training, Coordination & Implementation of Research
Prison Program: Development – Coordination
Media Center: Training – Education – Information
Monitoring & Licensing of Drug Programs
Development & Coordination of State Federal Funding
Development of Youth Programs
Statewide Program Coordination & Evaluation
University Training Programs
Development of State Assessment & Evaluation Center
ADMINISTRATIVE SERVICES
Paul Skelton
Purchasing
Finance and Accounting
Internal Audits
Management Systems
Personnel Services
Design and Construction Coordination
HRS DATA CENTER
PLANNING AND EVALUATION
David St. John
Community Medical Facilities Planning
Comprehensive Health Planning
Comprehensive Rehabilitation Planning
Research and Evaluation
*Personnel 65
CORRECTIONS
Louie Wainwright
Community Programs
Work Release
Study Release
Jail Inspection
2 Community Correctional Centers
Institutions
8 Major Institutions
19 Road Prisons
1 Farm Camp
*Personnel 2,360
**Services 13,500
YOUTH SERVICES
O. W. Keller
Community Services
Juvenile Probation and Parole
Stimulate Community Programs
Technical Assistance
Detention Inspection
6 Youth Services Centers
11 Halfway Houses
2 Non-Residence Programs
3 Group Treatment Homes)
Institutions
4 Training Schools
*Personnel 2,616
*Services 118,000
MENTAL HEALTH
W. D. Rogers, MD
Community Programs
Comprehensive Community Mental Health Centers
Out-Patient Clinics
Indigent Drug Programs
Mental Health Representatives
Institution Programs
State Mental Hospitals
Bureau of Alcoholic Rehabilitation
Alcoholism Treatment and Research Centers
Regional Out-Patient Clinics
Alcohol Field Representatives
*Personnel 5,927
**Services 80,000
RETARDATION
Jack McAllister
Community Programs
2 Regional Centers
Grants [illegible] Aid
Community Representatives
Facility Construction
Institutions
4 Training Centers
2 Hospitals
*Personnel 4,635
**Services 6,878
VOCATIONAL REHABILITATION
Craig Mills
Community Programs
Vocational Rehabilitation Services
Crippled Children
Medical/Related Services
Blind Services
Disability Determination
Talking Book Library
Consultation
Facilities and Workshop Grants
Work Evaluation
*Personnel 1,514
**Services 151,578
FAMILY SERVICES
E. D. Endsley
Community Programs
Financial Assistance and Social Services
Aged
Blind
Disabled
Children (AFDC)
Aging Services
Protective Services
Adoptions
Foster Homes
Medical Services
Nursing Care
Medicaid
Medicare
Commodities and Food Stamps
*Personnel 4,177
**Services 382,244
HEALTH
Wilson Sowder, M.D.
Community Programs
Health Services – Maternal & Child, Adult, Chronic Disease, Preventable Disease
Public Health Nurses
Dental Services
Sanitary Engineering
Licensure and Regulation
Vital Statistics
Laboratories
Institutions
2 TB Hospitals
*Personnel 4,444
**Services 4,889,000
CSDS PROJECT
Regional Administration
*Personnel 47
OTHER GOVERNMENTAL AGENCIES
Voluntary Participation
LOCAL SERVICE CENTERS
Voluntary Participation
PRIVATE AGENCIES
Client Services
Problem Diagnosis and Evaluation
Service Planning and Coordination
Follow-Up and Evaluation

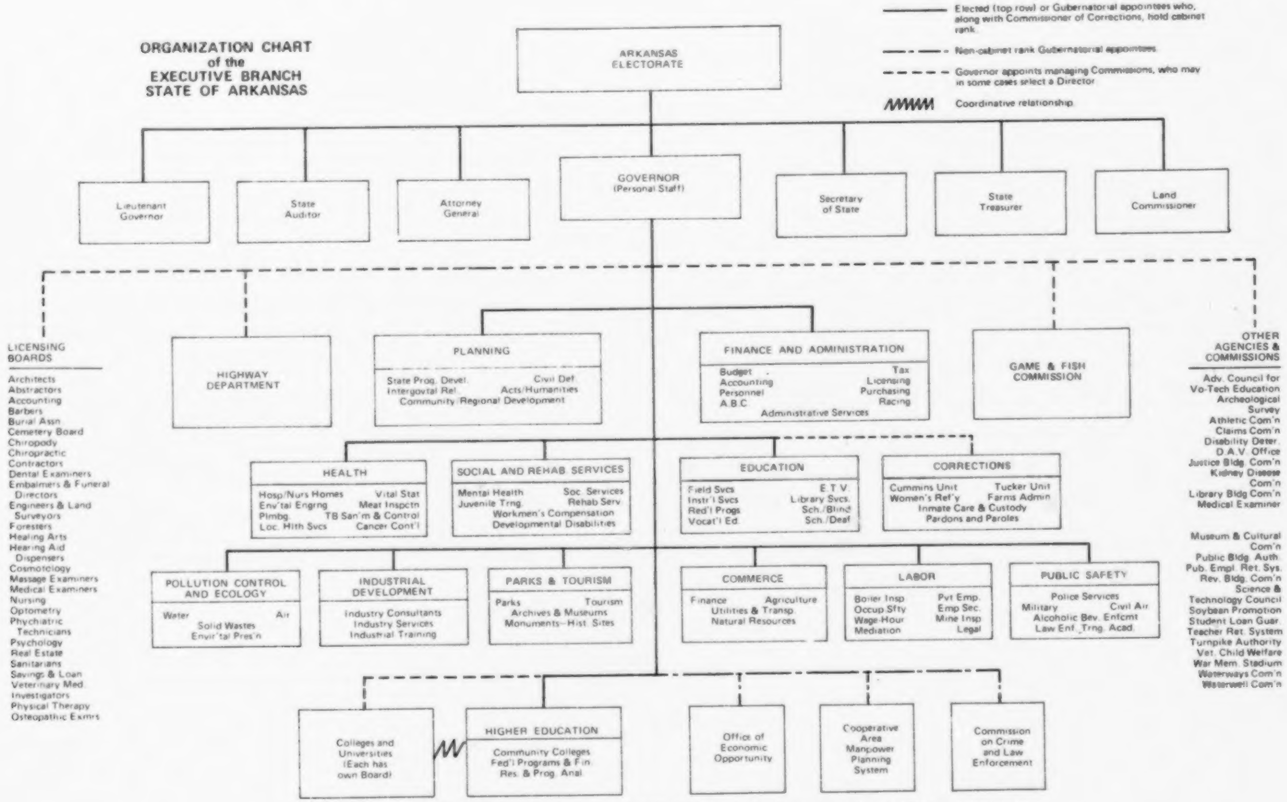
*Authorized Personnel Figures.
**Estimated Number of Persons Receiving Direct Services in FY 71-72.

Prepared by
Division of Planning and Evaluation

DEPARTMENT OF SOCIAL AND REHABILITATIVE SERVICES


Governor of Arkansas
Department of Social and Rehabilitative Services
Director
Mental Health Services
Commissioner
Administrative services
Mental Hospitals Division
Community Mental Health Division
Juvenile Services
Commissioner
Administrative Services
State Residential Services Division
Community Services Division
Workmen's Compensation Commission
Commissioner
Administrative Services
Early Childhood Development
Mental Retardation Dev. Disabilities Services
Commissioner
Administrative Services
Division of Residential Services and Centers
Division of Community Services
Rehabilitation Services
Commissioner
Administrative Services
Rehabilitation Services
Rehabilitation Services For the Blind
Comm. on Alcoholism
Research & Trng. Center
Kidney Disease Comm.
Social Services
Commissioner
Administrative Services
Medical Services Division
Programs Division
Food Services Division
Office on Aging

ORGANIZATION CHART
of the
EXECUTIVE BRANCH
STATE OF ARKANSAS


Elected (top row) or Gubernatorial appointees who, along with Commissioner of Corrections, hold cabinet rank.
Non-cabinet rank Gubernatorial appointees
Governor appoints managing Commissions, who may in some cases select a Director
Coordinative relationship
ARKANSAS ELECTORATE
Lieutenant Governor
State Auditor
Attorney General
GOVERNOR (Personal Staff)
Secretary of State
State Treasurer
Land Commissioner
LICENSING BOARDS
Architects
Abstractors
Accounting
Barbers
Burial Assn
Cemetery Board
Chiropody
Chiropractic
Contractors
Dental Examiners
Embalmers & Funeral Directors
Engineers & Land Surveyors
Foresters
Healing Arts
Hearing Aid Dispensers
Cosmotology
Massage Examiners
Medical Examiners
Nursing
Optometry
Phychiatric Technicians
Psychology
Real Estate
Sanitarians
Savings & Loan
Veterinary Med. Investigators
Physical Therapy
Osteopathic Exmrs
HIGHWAY DEPARTMENT
PLANNING
State Prog. Devel.
Civil Def.
Intergovtal Rel.
Acts/Humanities
Community/Regional Development
FINANCE AND ADMINISTRATION
Budget
Tax
Accounting
Licensing
Personnel
Purchasing
A.B.C.
Racing
Administrative Services
GAME & FISH COMMISSION
OTHER AGENCIES & COMMISSIONS
Adv. Council for Vo-Tech Education
Archeological Survey
Athletic Com'n
Claims Com'n
Disability Deter.
D.A.V. Office
Justice Bldg. Com'n
Kidney Disease Com'n
Library Bldg Com'n
Medical Examiner
Museum & Cultural Com'n
Public Bldg. Auth.
Pub. Empl. Ret. Sys.
Rev. Bldg. Com'n
Science & Technology Council
Soybean Promotion
Student Loan Guar.
Teacher Ret. System
Turnpike Authority
Vet. Child Welfare
War Mem. Stadium
Waterways Com'n
Waterwell Com'n
HEALTH
Hosp/Nurs Homes
Vital Stat
Env'tal Engrng
Meat Inspctn
Plmbg.
TB San'm & Control
Loc. Hlth Svcs
Cancer Cont'l
SOCIAL AND REHAB SERVICES
Mental Health
Soc. Services
Juvenile Trng.
Rehab Serv.
Workmen's Compensation
Developmental Disabilities
EDUCATION
Field Svcs
E.T.V.
Instr'l Svcs
Library Svcs.
Red'l Progs
Sch./Blind
Vocat'l Ed.
Sch./Deaf
CORRECTIONS
Cummins Unit
Tucker Unit
Women's Ref'y
Farms Admin
Inmate Care & Custody
Pardons and Paroles
POLLUTION CONTROL AND ECOLOGY
Water
Air
Solid Wastes
Envir'tal Pres'n
INDUSTRIAL DEVELOPMENT
Industry Consultants
Industry Services
Industrial Training
PARKS & TOURISM
Parks
Tourism
Archives & Museums
Monuments—Hist. Sites
COMMERCE
Finance
Agriculture
Utilities & Transp.
Natural Resources
LABOR
Boiler Insp.
Pvt Emp.
Occup.Sfty
Emp Sec.
Wage-Hour
Mine Insp.
Mediation
Legal
PUBLIC SAFETY
Police Services
Military
Civil Air
Alcoholic Bev. Enfcmt
Law Enf. Trng. Acad.
Colleges and Universities (Each has own Board)
HIGHER EDUCATION
Community Colleges
Fed'l Programs & Fin.
Res. & Prog. Anal.
Office of Economic Opportunity
Cooperative Area Manpower Planning System
Commission on Crime and Law Enforcement

This chart, prepared by Dr. Max Milam, shows organization of executive offices of state government after the 1971 reorganization law.

State Legislation and Procedures as They Affect The Developmentally Disabled

The Honorable Ernest H. Dean

FUNCTIONS OF THE LEGISLATURE

For a Developmental Disabilities Council to perform adequately in serving the neurologically handicapped, they should have a knowledge of the following functions of a state legislature:

1. The legislature has the responsibility to make sure that everything it does is in harmony with the federal and its own state constitution. It is also the responsibility of the legislators to update these documents to guarantee equal rights for all, including those with disabilities.
2. It has the duty of lawmaking. It may delegate this authority to other agencies of state government and/or local political subdivisions of government. Rules, ordinances and regulations fit this category. Appropriating money and levying taxes is part of the lawmaking authority.
3. It has the responsibility of formulating the general policy of state and local government. It provides the setting for debating public issues and for finding solutions to state problems. It is where most statewide political disputes are formally settled.
4. It has the responsibility of coordinating the role of the federal government in a statewide system of delivering services.
5. It is where the actions of state officials and state agencies are scrutinized.
6. It has the responsibility of initiating and approving interstate compacts and agreements.

Most state legislatures are becoming better organized to do the job required of them. They are increasingly capable of carrying out the functions as outlined. There are many aids available to the individual legislator and to the legislature as a body both while in session and between sessions.

These are:

WHILE IN SESSION	BETWEEN SESSIONS
Adequate staff to serve the legislature and its individual committees and, in many states, the individual legislators.	The staff additionally makes studies of problems which require legislative action.
Budget audit staff which determines revenue, identifies priorities and legislative intent, and reports on accountability of funds expended.	The budget audit staff also conducts a post-audit.
Legal counsel to draft bills and to search the code as related to proposed bills.	Legal counsel also represents the legislature in court action, makes a search of any one portion of the code on any subject, such as those relating to the handicapped, and makes recommendations for change.

In addition to the above aids, the following organizations prove beneficial in helping the legislator and the legislature perform their functional roles. These are:

1. Regional and national conferences on specific subjects.
2. Regional and national policymaking conferences.
3. Regional conferences to produce and approve interstate compacts and agreements.
4. The National Council of State Governments and its affiliated and cooperating organizations, including:
    a. National Legislative Conference which establishes a set of policy positions through seven functional committees. Two of these committees should have a strong relationship to programs serving the handicapped. These are the National School Finance Study Committee which is giving consideration to the matter of special education, including meeting the needs of the handicapped. The other is the Human Resource Committee. At least three of the other N.L.C. committees could give some consideration to policy positions in meeting the needs of the neurologically handicapped.
    b. The Education Commission of the States.
    c. The regional offices of the Council of State Governments. Six offices are operated, including one in Washington, D.C., whose purpose is to appraise the legislature of what the federal government does in relationship to programs which affect the states.
    d. National committees of the Council of State Governments, such as the one I chair, which is charged with interfacing what the 10 regional offices of the federal system do in delivering federal services to the states.
    e. A national committee on suggested state legislation.
    f. Then there is the Advisory Commission of Intergovernmental Relations which includes congressmen, senators, state legislators, cabinet officers, governors, mayors, and county officials which likewise relate to the whole government mix in serving people.

As a legislator, I receive reports, studies, policy recommendations and model laws from all these sources. I might add that, some, but not enough, consideration to the Developmental Disabilities program has been given by any of these committees or commissions. Much needs to be done by those interested in the developmentally disabled to effectively relate to the legislator, the legislature and the multiplicity of commissions and organizations serving legislators.

Any organization serving the developmentally disabled should know that the state legislature is the focal point around which needed change in serving the developmentally disabled program will come about. Each state legislature is keyed in on making sure state government is going to be a strong partner in our federal system–especially in regard to delivery of social services. *Therefore, it behooves those interested in developmental disabilities legislation to zero in on the state legislature and the organizations which serve the legislature in recommending where we go in providing needed services for the neurologically handicapped.*

To give the broadest coverage possible in the limited time for preparing this paper: (1) letters* were sent to legislators from several states asking for information regarding state legislation and the Developmental Disabilities Service Act; (2) actions taken by the national organizations serving the state legislatures were researched regarding legislative recommendations and the developmentally disabled; and (3) several national organizations serving handicapped children were asked for information. Drawing from this pool of information, each function of the legislature has been examined and the job being done by the states in relationship to the Developmental Disabilities program has been evaluated.

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*See appendix for a copy of a typical letter.

The Constitution

The Federal Constitution leaves the responsibility for delivery of social services to the states. One then needs to turn to the state constitution. The only references to the neurologically handicapped in Utah's state constitution are four subsections as follows:

1. "Idiots, insane persons and certain criminals are ineligible to vote."
2. "Idiots are ineligible to hold public office."
3. "The legislature shall provide for the establishment and maintenance of a uniform system of public schools. These public schools shall include: kindergarten, common schools, high schools and universities. The common schools shall be free. The other departments of the system shall be supported as provided by law."
4. "Reformatory and penal institutions and those for the benefit of the insane, blind, deaf and dumb, and other institutions, as the public good may require, shall be established and supported by the state in such a manner and under such boards of control as may be prescribed by law."

Other states have had constitutional revisions and updated the language related to the handicapped.

Recommendation: The Developmental Disabilities Council should take a leadership role in supporting legislation necessary to bring about these constitutional changes. If the people in any one state will not support a constitutional convention, they should be asked for approval to recodify the language of the state constitution (emphasis placed upon language relating to developmental disabilities).

Lawmaking: State and Local Government

Code Review – Any one state will have many divisions of state and local government charged with delivery of services to the neurologically handicapped. Many laws have been passed relating to these agencies of government dealing with mental retardation and some with the other neurological handicaps.

Examples in the Utah Code:

Cruel treatment or neglect of an idiot is a misdemeanor.

Annulment of adoption is permitted within five years where a child is afflicted with feeble-mindedness as a result of a condition existing prior to adoption.

There is not one statute in Utah relating to cerebral palsy. There are others which are equally degrading to the handicapped. However, some sections of the code are very satisfactory. Some states have adopted model laws relating to the handicapped. Other states need to review all statutes on the books and adopt a model law governing not only education, but also health services, and the role of the institution(s) in providing backup services for community programs.

Budget – Many states appropriate money to many agencies to serve the handicapped. In many instances, agencies compete for the available money. When this happens, the wise money-conscious legislators play one agency against the other and both agencies then end up short of budget needs to serve the handicapped.

Recommendation: A master plan should be developed wherein all agencies serving the handicapped can interrelate to the best advantage of the total program.

Developmental Disabilities Councils in each state should assume the responsibility for looking at a total legislative program to serve the neurologically handicapped. They should communicate their recommendations to the legislature.

Setting General Policy of State and Local Government – Each state legislature, if it has not already established the policy for a statewide delivery system serving mental retardation and the other handicapping conditions, should do so. In the state policy, provisions should be given to the role of the institution(s) in providing a battery of backup services for local community programs. Much of this paper will hinge upon this concept.

The legislature has the responsibility of defining what state agencies will do to delivery services at the local level of government.

It has the further responsibility of defining the role of local government in the delivery of services to the consumer.

Each state legislature should provide by law:

(1) That the top administrators in education, vocational rehabilitation, welfare, health, vocational education and mental retardation, etc., should come together in statewide planning and coordinating efforts of all divisions of government for a unified delivery system of services.

(2) An interagency work committee should be established to deliver services according to the policy established under number one above.

Another aspect relating to the function of setting state policy might be that of settling disputes between government agencies providing services. To settle these disputes, usually the legislature holds hearings where the public can voice its opinions.

Recommendations:

(1) Those states which have not balanced and integrated state and local delivery systems of services to the developmentally disabled should see that it is done. Developmental Disabilities Councils should call upon the state legislatures to accomplish this end.

(2) Another important consideration in setting policy, as related to the developmentally disabled, is the role of the state institution(s) in a statewide system of delivering services to the developmentally disabled.

An institution should be the focal point around which the following programs can be built and deployed throughout the state or even throughout several states:

(a) Medical research, medical training and genetic counseling. Here the institution and its clinical laboratory, the state's university hospital and medical school and the state department of health must serve as a consortium in finding causes of mental retardation, cerebral palsy and epilepsy, etc., and implementing programs to minimize the cause once it is detected.

(b) The institution should serve as a training ground for professional personnel who will work in the field. This should apply to undergraduate and graduate students in the fields of medicine, psychology, law, engineering, social work, special education, speech and hearing, recreational and occupational therapy, etc.

(c) The institution can serve as a resource to parents who reside close to the institution for day programs where there is no program available at the community level.

(d) The institution can serve families who need short-term care for a family emergency, a planned vacation, or for other needs on a guest basis for a short period of time.

(e) The institution should move in the direction of placing severely retarded adults in small residential homes near the institution where the institution serves as the base for programs, but where the residents live in a small group home with houseparents. These residents need 24-hour care, but the residential program can be much more meaningful with the institution serving as backup to the group home.

(f) The institution, in cooperation with vocational rehabilitation services, should establish sheltered workshops at or near the institution. This facility should serve the resident of the institution and community clients.

(g) Retarded individuals who reside in nursing homes should utilize the facility of the institution(s) for such activities as church, shows, dances, picnics, recreation, etc.

(h) The institution(s) and all its resources should serve community clients in terms of diagnosis and evaluation. Community clients should be included in medical clinics conducted by the state department of health and/or the university hospital and held at the institution(s).

(i) The institution(s) should open facilities, including, recreational parks, gymnasiums, church facilities, etc., to the public so they can identify with the institution(s).

(j) The institution(s) should open doors to the university, high school and common school students for workshops on mental retardation.

Role of Federal Government in State Affairs – The legislature has the responsibility of coordinating the role of the federal government with a statewide system of delivering services.

The legislature finds itself plagued with almost endless numbers of titles and subsections of titles to federal acts which relate to programs serving the handicapped, disadvantaged and elderly. Making sense out of what the federal government does, as they are responsible for initiating programs into the states, causes the state legislature *"fits."*

Another major concern of the state legislatures relates to federal and state court cases declaring unconstitutional state laws and state practices of meeting the constitutional rights of people. Note needs to be made of the rash of federal and state court cases declaring state and local school finance formulae unconstitutional.

Special attention is given to meeting the needs of the handicapped as evidenced by the Pennsylvania and District of Columbia "right to education" cases. The upcoming session of the 50 state legislatures will be wrestling with this concern. In Utah we are looking at a weighted pupil expenditure formula which would give extra attention to those with disabilities.

Another major consideration which should be made in the school finance formula is to provide preschool and health programs for those under six years of age. A major breakthrough needs to be made to serve infants and preschool handicapped children, especially to identify and treat the cause of their handicaps at as early an age as possible.

The legislature, in looking at the Developmental Disabilities Service Act, does so with these questions in mind:

1. Once we get the program started and established will the federal government cease to fund it, thereby causing the state to provide the means of continuing it?

2. Why should the regional offices of Health, Education and Welfare, responsible for the act, dictate the membership of the committee which will advise the state and/or local agencies of government in administering the program?

Recommendations:

1. Developmental Disabilities Councils should wait upon Congress with two objectives in mind: (a) to fund social service legislation based upon needs–i.e., so long as the need for the program exists they should continue to fund the program thus alleviating the need for the states to pick up programs the federal government initiates; and (b) to work out a better system of attaching

appropriations to bills which are enacted, and of handling presidential vetos of appropriations bills.

2. The federal system responsible for the Developmental Disabilities Service Act should be advisory to the state agency in administering the act and should not dictate procedures under which the state agency will act.

Scrutiny of State and Local Government

The legislature is, by using professional staff, able to scrutinize state and local government agencies. They have staff which can perform the following duties to aid the legislature:

1. Designating legislative intent as to what appropriations or tax authority should be used for.
2. Conducting a *post-audit* to guarantee that the money expenditures were properly accounted for and they were spent according to legislative intent.
3. Reviewing the rules and regulations advanced by state and local agencies of government to again determine that they represent the interests of the legislature to the public.

Recommendation: Developmental Disabilities Councils should strive to harmonize relationships between state and local governments to serve the interests of the developmental disabled. Federal, state, and local governments should be partners in the Developmental Disability program. No one should be short circuited in the delivery of services to the program. All three levels of government should be partners in the delivery system.

Interstate Compacts and Agreements

Very little, if anything, has been done within states have joined together, either by agreement or compact, to provide specialized services for certain types of handicapping conditions. An example which could result in an agreement along this line might be specialized services for the blind, deaf, and severely retarded. Another could be a setting with strong seizure control medication, education and recreation for those with excessive seizures who are extremely retarded.

Recommendation: Each region of the Council of State Governments should be encouraged to:

1. Hold conferences of Developmental Disabilities Council members, administrative people responsible for the act, and legislators, to develop a close working relationship.
2. To strive for interstate agreements to provide speciality programs including (a) research; (b) education (for all health professionals, including M.D.'s); and (c) special care programs serving several states.

LEGISLATIVE INQUIRY OF SEVERAL STATES

Questions were posed in letters sent to legislators from 20 states regarding the DDSA program in their state. This was done to get a flavor of state legislative action as a result of DDSA.

Fourteen of the 20 states responded, many of them after the paper was first presented at the national conference.

Questions asked were:

1. *What are the problems and issues concerning DDSA in your state?*
2. *What are legislative concerns regarding the DD act?*
3. *What is the role of state institution(s) in serving MR?*

Much information was received from either the legislator to whom the letter was addressed or from the state agency to which the legislator referred the letter for reply.

Some of the responses from the several states are included:

State of Washington Reply – November 2, 1972

"We feel far less money is available now under the DD Act than was previously available for our state. Where previously rather large grants were available for MR construction and assistance programs, the grants now available through the DD Act appear to be much less. This now becomes a matter of legislative concern.

"There is a federal requirement of establishing a state planning and advisory council. A probable legislative concern in this instance would question not only the need for a state council to oversee the administration of a program of this magnitude, but it would also question the diversion of the funds necessary to support the council from the basic objectives of the program. Not that the Legislature would feel that nothing could be gained from planning and administration help to the program, but a parent council could stifle innovative administration in the field, as well as detract important dollars from other worthwhile objectives.

"A second additional legislative concern may be expressed in the limited application of funds in the total field. No present quarrel exists with the application (which is controlled by the Secretary, HEW), but if the list does not expand to allied disability fields some concern may be expressed. From our position (although this certainly may not be the case), it is our understanding that cerebral palsy, mental retardation, and epilepsy are the primary recipient disabilities. Other physical and mental disabilities exist, including multiple disabilities, which are not clearly delineated as eligible fields of funding. Perhaps expansion is envisioned, but if not, this may be an area of concern.

"Finally, some discussion must be directed toward the changing state program as it relates to the changes evident at the federal level. The state program has been in evolution. From a former major emphasis on institutional care, the state program is now directed toward local and community projects with cooperative arrangements in allied fields to establish work potential and rehabilitation. From our own understanding of the changes operating in the state program, one very important aspect is the establishment and organization of service staff who can assist in the transition from direct institutional care to group homes and community projects by servicing the developing local catchment areas. From the legislative view, concern is expressed that sufficient state and federal funds may not be consistently available to effect an orderly transition in the program. Part of the concern exists because of the eventual status of the present institutional plants and the requirement of increasing state funds to maintain a sound and livable capital condition. Further, as the residential populations of the present schools for the mentally retarded are reduced, the per capita costs are increasing at an alarming rate. If the main thrust of the state developmental disabilities program continues to be toward small, community-based facilities, it is imperative that federal aid continues and in sufficient amounts to ease the transitional burden."

State of Ohio reply – November 2, 1972

"1. Proposed expenditures under new Federal Law

The Ohio State Plan for Developmental Disabilities was submitted to the Social and Rehabilitation Service in July, 1972. It provides for expenditures in fiscal year 1973 as follows:

	Expenditures from all sources	Expenditures of federal funds
Planning	$ 215,000	$170,000
Administration	260,000	200,000
Services	738,362	567,362
Total	$1,213,362	$937,362

In the development of a comprehensive system of services, the top priority will be given to funding training workshops and hiring consultants to perform specific tasks in relation to resource development. Services funds are to be used to support individual projects that show promise of contributing significantly to case management services, protective services, personal advocacy services, information and referral, follow-up services, family supportive services, education and training, day care, recreation, sheltered employment, screening, diagnosis, evaluation, and treatment, and transportation.

"2. New Directions in Serving the Mentally Retarded

Concern for the preservation of the rights of handicapped persons and the provision of protective services appear to be the major new developments in this area. Under Ohio's new State Plan for Developmental Disabilities, the principle of variation in the capacity of individuals to exercise human and civil rights is expressed, and a Personal Advocacy System under a nonpublic agency is proposed, to see that the individual gets the services he needs. The 109th General Assembly enacted H.B. 290 to provide for the development of a system of protective services. (We are considering the substitution of community services for institutional care to be a well established direction, rather than a new one.)

"3. Problems

The Planning Director and Administrator of the Developmental Disabilities program is concerned that funding for this program is uncertain for the years after fiscal 1973, and that funds must be requested on a quarterly basis.

A problem for the General Assembly in attempting to determine program priorities and revenue requirements is the confusion of overlapping programs planned by state and local agencies in response to Federal incentives. Although the Developmental Disabilities Services and Facilities Construction

Amendments of 1970 require the states to describe services being provided to persons with developmental disabilities under eight or more other State plans, and prohibit duplication or replacement of other programs, no information is presently available concerning developmentally disabled persons served in such programs. Each type of service may be provided by at least two other federally-supported programs in Ohio, and some may be provided under as many as 10 programs. In addition, federal allotments may be distributed to other agencies and contracts made for the provision of services. It is possible to envision the Developmental Disabilities Office reimbursing the Department of Public Welfare from Developmental Disabilities funds for counseling services to developmentally disabled persons on public assistance and a local Welfare Department reimbursing the local Mental Retardation Board from Social Services Funds for the same services.

"4. Role of State Institutions

The state institutions for the mentally retarded had an average daily resident population of 8,993 in fiscal year 1972. The family care program was serving 512 persons at the end of the year. Although the average population declined from about 10,000 during the last five years, the implications of the decline may be misread, since the counties remain under a quota system for admissions. Three of the six institutions in Ohio operate community service units, providing out-patient and after-care services to a total of about 1,400 persons. One of these units provides partial hospitalization."

State of Montana Reply – October 30, 1972

1. What are the problems which relate to the program in your state?

"The chief problems we have had are involved with *time and space*, problems which you share. Basically, our organization is not yet strong enough to be able to supply close enough supervision to our many individual programs. We do not have the *flexibility of response* that is necessary. We depend on local volunteer supervision and this is not adequate of and by itself. We have overcome this problem to some extent by employing a person who literally lives on wheels with the overall assignment of "managing" these services throughout the entire state.

"A further problem is a *lack of full and complete cooperation* between the departments of state organization; there do exist the inevitable jealousies. We find that once we can get below the departmental level, that the bureaus within the various departments can cooperate quite well between departments.

"We have, of course, the inevitable problem of *not enough state or local dollars TO PURCHASE AVAILABLE FEDERAL DOLLARS.* Therefore, many deserving local efforts must go unfinanced. In isolated instances, we do have local effort which exceeds our ability to bring our limited ($100,000) DD funds to that specific project. This is tough decision making, but it is in keeping with our philosophy of a broadcast effort across all regions."

2. What is the role of your Institution(s) in serving MR, including its(their) relationship to community programs?

"As you know, Montana is unique in having a single director of both its major institution(s) and the community programs. *The role of the institution is defined as being the reverse image of community programming.* That is, the institution must be prepared to offer services to the needing people of the state when the community does not or cannot offer that service. To this extent, our institution is seen as being flexible and willing to get out of being a provider in instances when the community is capable of being the provider. The organization of the institution is a direct reflection of the organization of the state. Our state has been divided by executive decree into five distinct regions and the organization of the institution is also divided into the same five units of management."

3. What are the legislative concerns regarding the DD act?

"We have four major concerns, none of which have been resolved: One, we feel that the autonomy of the mentally retarded or the developmentally disabled must be preserved and not subsumed under some major generic service category such as vocational rehabilitation. Our second concern is whether to legislative sanction the developmental disabilities council or to keep it at its present non-statutory level. Our third concern is to devise the means by which local and/or state funding can be made available to the Division of Mental Retardation in a sufficiently flexible form that it can respond to the many available federal efforts. Our fourth concern is that there is always the overriding concern that through the use of federal funds we develop programs which might cease to exist with possible disappearance of federal funding."

The State of Colorado Reply – December 11, 1972

"The major problems relating to the Developmentally Disabled Program in Colorado are thus:

1. Frequency of change in federal directives – the directives emanating from HEW, Social and Rehabilitative Services, have been frequently changed, making it difficult to establish state policy consistent with the federal guidelines. For example, HEW is broadening the categories of persons eligible for assistance. This uncertainty as to the clientele who are to receive services under the program does not promote effective planning at the state level.

2. Role of state agencies, etc. – until a recent Executive Order issued by the Governor, the role of state agencies, the State Planning and Advisory Council, and the staff was unclear. This has resulted in inadequate staff support to develop planning and coordination of various state and private agencies. However, through the Governor's Executive Order, the Department of Institutions has been designated as the agency which shall administer the State Plan for the provision of services to eligible clients while the Department of Health has been directed to administer the facilities construction portion under the state plan. The Governor further directed the designated state agencies to provide staff support to accomplish the responsibilities of the respective state agencies. The Governor's Executive Order should clarify agency responsibility and provide adequate staff support within agency capabilities.

3. Problem of inserting new legislation into state budget cycle – an initial problem arose in requesting state funds to match federal appropriations under the DD Act, as the federal legislation was passed after state budget requests were prepared. Additionally, three fiscal years of funding have been compacted into an 18 month period of time. It is not anticipated that there will be future problems concerned with the budget cycle, however.

4. Lag in capital construction – each state had the option of utilizing federally appropriated funds for services and construction up to 50 percent of an annual appropriation. Councils and agencies were encouraged by the federal representatives to address services until appropriations were sufficient to warrant facility construction. This position was adopted by Colorado. The Council indicated that a federal appropriation of $7,800,000 would be more appropriate to consider facilities planning than the present appropriation of $180,000. Until such time as the federal appropriation is sufficient, facility planning and construction is at a standstill.

5. Lack of agency coordination – at present, several state agencies provide services to persons with developmental disabilities. There is currently an attempt to identify those agencies which provide the 16 discreet services and, once identified, encourage greater coordination of these various state agencies.

6. Lack of data adaptability – much of the data requested of the state program for developing the required annual State Plan by HEW has not been programmed into the computers operated by the relevant state agencies, therefore, requested data has not been available. Obtaining statistics is dependent on other means of surveying, etc.

"In explaining the role of state institutions in serving mental retardates, the role of the 23 community mental retardation centers should be emphasized. These autonomous centers are funded by the state on a per pupil basis ($840 per client) to provide services to those mental retardates for whom institutionalization is unnecessary. For providing services to those mental retardates who qualify for funding under sections 4A and 14 of the Social Security Act (welfare recipients and the needy blind), the mental retardation centers are funded by matched federal and state sources on a 75-25 percent basis. With these funds, the centers can purchase the professional services of private agencies, if such are available, or may develop their own programs if professional service agencies are not readily available in the area. The state mental retardation institutions, of which there are three, provide services to those individuals for whom institutionalization is required.

"Funded by state and federal appropriations, these three institutions generally develop their own programs, yet do purchase some services from other agencies–most notable is the purchase of special educational services from school district.

"Under development in Colorado is the Hospital Improvement Program (HIP), by which the Division of Mental Retardation rents group homes for the placement of institutionalized clients. Associated with HIP is the Normalization of Community Residential Services program, which is addressed to the service needs of all placement facilities for mental retardates in the state, including those individuals placed under the HIP program. Both of these programs are totally funded by federal appropriations.

"Providing diagnostic and evaluation services, through which the developmentally disabled are identified and channeled through the various community and institutional treatment programs, are the community diagnostic and evaluation clinics of the Department of Health. These clinics are financed by federal and state funds through the DDA act on a 90-10 percent basis (poverty area) or on a 75-25 percent basis in more affluent areas. These federal funds will terminate in July 1973, however, and the state is being requested to assume funding of this program.

"Trends in methods of serving mental retardates and other neurologically handicapped individuals has not been surveyed in this state and thus question #5 cannot be answered.

"A legislative problem does exist in that the General Assembly has failed to authorize state funding to match federal appropriations. One explanation, advanced by the staff of the Joint Budget Committee, for the General Assembly's not providing matching state funds is the inadequate justification for such in the budget request prepared by the Division of Mental Retardation."

State of Iowa's Reply – December 12, 1972

"The state institutions admit MR's (a) in need of short-term intensive training for greater self-sufficiency, (b) whose disabilities are so severe or numerous that home care is unfeasible, (c) by court commitment, or (d) when community facilities and programs to meet the individual's needs do not exist.

"Each evaluation for admission to a state hospital-school produces a care and training prescription, and a recommendation for either community programming or institutional admission. Community programs are encouraged and assisted by Mental Retardation Specialists, based at the institutions, who coordinate these developments in light of the area's needs. State money is not offered for the development of local MR programs, which usually are financed by local government, organizations such as local Associations for Retarded Children, or private operators. The State Hospital-Schools, functioning as MR Resource Centers offer training and consultation for community program staff, speakers for local meetings, parent training in home care at the institutions, and public information services on the condition of mental retardation.

"A major trend worldwide–and in Iowa–is to reverse the institutional movement back toward community life and services, and providing for the retarded through mainstream rather than specialized-programming for them. This allows the institutions to become Resource Centers, offering a wide array of supportive services to community programming, providing intensive short-term training for the MR and their families, and also serving the small number of long-term patients with multiple handicaps, for whom life maintenance services are primary concerns. Most handicapped can live in a family setting, if there are local services available to serve their special needs.

"An Iowa legislative committee is currently working on a bill which will place DDA, Mental Retardation, Mental Health and the Mental Health Authority in a separate department of state government. This would constitute further disruption of Iowa's DDA effort, and cloud the distinctions among those conditions in legislators'–as well as the public's–minds."

State of Tennessee Reply – December 5, 1972

"The chief problems encountered with regard to Developmental Disabilities Service Act programs in Tennessee are:

1. Valid identification of handicapped persons for planning purposes.
2. Amount of money available to Tennessee to adequately meet needs as spelled out in the act.

"The three state institutions continue to serve greater numbers of the mentally retarded than any other combination of agencies. In recent years, and particularly since the advent of the Developmental Disabilities Service Act, there is a growing emphasis on decentralization, and the institutions through their outreach programs are making major contributions toward the return of the mentally retarded to their home communities.

"In the legislative area, we are concerned primarily with the outcome of the Mandatory Education Act in Tennessee.

"The emphases which dictate the direction in which Tennessee is trying to go are: (1) wide local community involvement, (2) cooperation to avoid duplication of effort, (3) accountability in areas of both programming and funding, (4) establishment of procedures to assure quality control in planning and programs, (5) decentralization, (6) comprehensive services in geographical proximity to the home communities of developmentally disabled persons."

State of New Mexico Reply – October 25, 1972

"Our main problem is that of matching funds which will be discussed in reply to your sixth item.

"The Department of Hospitals & Institutions administers the MR programs and institutions and is now actively moving toward community programs for the MR and DD population. This Department has a pilot program in a four county area, legislatively funded by the state, which is a community program providing comprehensive services including residential facilities. The program is presently being expanded to seven counties to include an entire planning district. The Departments of Education, Health & Social Services, and Hospitals & Institutions work cooperatively in providing the comprehensive services of this pilot program. The Department of Hospitals and Institutions now has 17 other programs throughout the state which are providing some of the basic MR services and it is planned that in five years comprehensive services will be available statewide.

"A marked thrust is seen in the direction of public and private agency coordination of programs, services, and funding as mentioned in Item 1. The Developmental Disabilities program has been instrumental in involving Areawide Comprehensive Health Planning Agencies as the catalytic agent for this coordination. Public health associations should also be involved but the problem here is one of convincing the multiple generic organizations and professions that habilitation and rehabilitation of the handicapped is a public health problem.

"To date, there has been no legislative concern regarding the Developmental Disabilities Act. The administering agency was designated by Executive Order and no appropriation for DD was specifically requested. As noted above, an appropriation was passed for a pilot program for MR. In 1967, SB-199 was passed, thus creating the Mental Retardation Program Coordinating Council. However, the Council has not been funded and is not perceptibly viable. Many of us actively planning in the fields of MR and DD feel that categorizing so specifically for legislative purposes is a detriment to planning and funding comprehensive services for the developmentally disabled (which includes the MR) individual. We recommend that all reference to MR be deleted from legislative action and DD be inserted."

State of Florida Reply – October 31, 1972

"Florida's state institutions that serve the mentally retarded are administered by the Division of Retardation which is the administering agency for our DDSA program. As the services provided to the citizens of Florida by the Division of Retardation are becoming community focused, our institutions are becoming regional and community service centers, with an emphasis on the coordination of programs with local organizations and other state human service agencies that provide services to the developmentally disabled. The deinstitutionalization and humanization of services to the developmentally disabled is a major thrust of the Division of Retardation being accomplished by trying to serve the developmentally disabled in their own communities."

State of Texas Reply – October 27, 1972

"The basic problem confronting us in Texas appears to be the lack of an integrated service delivery system on a geographic basis. We have a series of parallel and sometimes overlapping partial federal, state, local, public and private systems which often deliver fragmented services. The Developmental Disabilities legislation points the way to solving this problem through its emphasis in interagency cooperation in planning and implementation, but the current funding levels only allow us to scratch the surface.

"Our basic legislative concern is that Congress may see fit to extend this law for an additional three to five years. We would like to see provisions which would encourage us to make some longer term funding commitments to local agencies. Our concern is that Congress will take a dim view (with justification) of the fact that many states have been extremely slow in spending their developmental disabilities monies.

"In brief, we feel in Texas that the Developmental Disabilities Act is one of the most creative and workable that has ever come along. Our experience has been highly positive, and we hope that Congress will give us the opportunity to demonstrate the effectiveness of this type of unique federal-state partnership even further."

State of South Dakota Reply – October 25, 1972

"In regards to problems related to our state, I believe we have many of the similar problems that your state might have. Of course, the limited funding poses a great problem, however, I do believe that the concept of the Developmental Disabilities Act far outweighs the actual funds that we receive in benefits to the handicapped people.

"The lack of guidelines, regulations, and leadership from the Washington level has provided South Dakota with numerous problems in attempting to administer this program. Also the lack of time and staff to accomplish much of the detailed planning and coordination in developing the state plan is a great problem.

"I believe that South Dakota is beginning to totally change its emphasis from that of large scale institutionalization to the provision of community programs and services. Our institutions' population is being reduced and should be reduced substantially more in the next few years. An emphasis is very definitely being placed on the use of existing generic services rather than the continuous development of specialized programs for the handicapped. Our goal is to provide the developmentally disabled with the ability to use those normal services which are available to everyone within South Dakota. Proposed statewide legislation providing for equal state and county support of community services will be introduced in our state legislature this year. If passed, this legislation will be the key in the development of alternatives to large scale and long term institutionalization.

"Our state hopes that the Developmental Disabilities Program will be passed again in Congress, however, we do hope that more concern will be given to rural states and their special programs."

State of Alaska Reply

"I think if there are any primary problems in Alaska, they relate to the small amount of money which is awarded to the state on a population basis and rather inadequate in combating the entire problem. Related to this small amount of money is the rather cumbersome mechanism demanded by the federal government, namely the Governor's Planning and Advisory Council on Developmental Disabilities which insists upon personally allocating almost every penny of the money. The small amount of money is aggravated by the high cost of living and transportation in Alaska.

"In comparing our programs for the Developmentally Disabled in Alaska with those in our neighbor states and actually all of the lower 48, we feel that we have made a great deal of progress. With no waiting list and with two institutions whose programs are completely rehabilitation rather than custodial and with the fluidity mentioned above, we feel we are in an enviable position. In the next few years we should be able to fill in the gaps in services if we work aggressively on this and have the support of our state officials and legislators in the capitol."

State of North Dakota Reply – October 18, 1972

"I do have a few thoughts on the subject. My contact with the committee set up to plan the use of the DD money and process grants has been minimal. It has been enough however, to feel strongly that somehow the grants seem to go to existing programs for expansion. While our state has never done enough for the retarded whose needs are almost limitless, it has had a better program than most states. I had hoped DD would emphasize some new areas such as Learning Disabilities, Cerebral Palsy, etc. The money seemed to go to group approaches but in our state we have all these isolated cases scattered around untouched by group action. I guess what I'm trying to say is that I wanted some kind of a tuition fund set up with that money for kids who may have to go out of state for sheltered workshops, etc. I've been in the position of trying to help with some severe or multiply handicapped people for whom there is nothing instate, vocational rehabilitation, welfare, etc., just pass these people back and forth and refuse to assume responsibility.

"I would like to see some kind of interstate contract set up with a portion of the DD money to provide a facility for those cases each state has in not too great numbers but with no resource available to help them in their own state."

State of Arkansas Reply – October 31, 1972

"I cannot say that we do not have problems in the DDSA program in Arkansas, however, I can say that these problems are minimal. It seems that our biggest problem is not having enough DDSA money to fund all of the project requests. I understand that some states are not using their DDSA money as fast as they should. This is not the case in Arkansas. We find that in one grant's period we receive requests for about twice as many projects, dollar-wise, as we have money to fund. Another problem that we are wrestling with from time to time is the national problem of definition of 'other neurological impairments.'

"In respect to new directions in serving the Developmentally Disabled, we feel in Arkansas at this time our most pressing problem is getting services to the communities and then to upgrade these services as quickly as possible. We are attempting to use the Developmental Disabilities money as gap filling money to fund projects that cannot be funded through other sources.

"Legislative concern regarding P.L. 91-517 would include the problem of appropriating up to the authorized levels in the legislation; better definitions of terms such as other neurological handicaps; and more definition of the duties and responsibilities of the Planning and Advisory Council."

SOME NEEDS WHICH MUST BE RECONCILED IN THE SYSTEM TO ADEQUATELY SERVE THE NEUROLOGICALLY HANDICAPPED

Service Programs

Although much progress has been made in recent years towards alerting legislators to the needs of the neurologically handicapped, much more needs to be done. The Developmental Disabilities Service Act Councils should take aggressive action in alerting their legislators to the needs in any state which has not accomplished the following:

1. Adequate funding to establish an accurate registry of the developmentally disabled according to the handicapping condition.

2. Sufficient trained personnel to meet the needs of all within the registry.

3. Established pre-school programs for the child and programs for

parents in health care, genetic counseling and education.

4. Established work, recreational and educational programs for the out-of-school handicapped.

5. Adequate community service programs utilizing the state agencies as back-up services to all community programs. Such agencies as the state mental retardation institutions, department of health, department of welfare, state medical colleges and hospital should be included in this delivery system.

6. An institutional program with a strong community-centered program with a free flow of students back and forth to adequately meet the needs of all. Make sure institutional programs improve on a parallel basis with community programs.

The legislature must define the role of the institution as a community related program—that is, the services of the institution should be focused upon community clients who need service not available near their own homes. Over the past years parents have sought services from our state schools for the following reasons:

a. The retarded individual is a physical or psychological burden and represents a problem of health to the parents.

b. The retarded individual represents a threat to the welfare of the family.

c. The retarded individual constitutes a social problem and is in need of social controls.

d. The retarded individual is unable to obtain an adequate program for his needs near his own home.

Under the philosophy that an institution is a part of the community, it then follows that institutional residents should have full access to all community facilities and programs and that institutional programs should be available to the community.

Research and Training

Although this is not a delineated responsibility of the Developmental Disabilities Council under the Federal Act, the State Developmental Disabilities Councils must take an active role in balancing these programs in the statewide system to more adequately serve the neurologically handicapped.

Training – *As yet, relatively few medical schools expose their students to the practical evaluation, recognition and management of persons with chronic neurological handicaps and retarded development. The acute disease, the critical case, the rare syndrome and the immediate threat to health, take precedence and too often describes the physician's concept of his total patient responsibility. He has little preparation and even less interest in assisting the patient for whom he cannot cure or correct the defect.*

Greater effort in all medical training situations should be made to train students to: (1) recognize defective growth, (2) know and treat promptly those acquired diseases which can cause brain damage, (3) search diligently for new explanations and conditions of retardation, and (4) be aware of and prepared to work with state and private programs for the evaluation, education and habilita-

tion of persons with neurological handicaps.

Again, the legislature should take positive steps to see that adequate training is included in the curriculum and laboratory experience of every medical student who will be licensed and practicing where he may be treating pregnant women and infants. This can be done through licensure laws and examinations by licensing boards.

Still another, even greater problem rests in the education of the practicing physician who has little or no training in pediatric neurology, yet is treating pregnant women and infant children.

Research – Developmental Disabilities Councils can go the extra mile and help the state legislature realize the importance of research.

What is on the horizon in research and mental retardation? Recent classification figures from the mental retardation research facility at Waverly, Massachusetts, and from our own unit in Utah, indicate that the causes of retarded development below the 50 IQ range are as follows:

Acquired disorders, such as lack of oxygen at birth, nervous system infections, prenatal infections and direct injury – 30% (treatable)

Inherited metabolic and endocrine disorders, such as PKU, abnormal fat storage, thyroid disease and sugar metabolism defects,– 5%

Classifiable malformations, such as Down's syndrome (mongolism), other chromosome abnormalities, myelomeningocele and multiple major malformations – 25%

Unknown causes, such as those associated with epilepsy, minor malformations and undefined familial factors – 40%

The acquired disorders should be considered preventable, but even today many cases of treatable meningitis and complications from head injuries go undetected for too long and brain damage results. Practicing physicians on the "firing" line need to be alerted to the urgency of these situations. *Infectious disease research groups need major support to further investigate and find effective treatment for virus diseases which cause grain damaging encephalitis. We are on the verge of preventing many virus diseases altogether, if research funding can be promoted.*

Research into the genetic and acquired causes of epilepsy is a desperate need and requires combined efforts of mental retardation foundations, epilepsy foundations and public, state, and federal funding.

Congenital malformations. *Major and minor defects of body development are found among a major segment of our residential populations.* Classifiable and nonclassifiable malformations comprise 47% of the entire group under 50 IQ. This includes chromosome abnormalities and many others which appear to have familial factors. Dr. Warkany's newly published text, *Congenital Malformations,* and the emphasis placed by the National Foundation on Birth Defects, epitomize the magnitude of the problem and the frustrations met by medicine in dealing with this problem. *Genetic factors play a role and there are still many undefined acquired factors,* as exemplified by relating German measles in pregnant mothers to their malformed offspring. Despite advances in bone, heart, intestine, and kidney corrective reconstruction and transplantation which have helped many persons, we cannot reorder the malformed brain. We need to identify predisposition to malformation and prevent its occurence when possible. This is simply another example of funds being needed for research in the area that counts–prevention.

State legislatures must balance medical research and training of the medical student and the practitioner into a desired medical approach serving the neurologically handicapped. Yet, no legislature within the 50 states has given the slightest attention to medicine and its responsibility to mental retardation. It's time for a breakthrough in this vital reform program.

CAUTIONS, SUGGESTIONS AND RECOMMENDATIONS

Developmental Disabilities should, in the opinion of this writer, go beyond the true definition of the federal act and embrace all dimensions of programs which can serve the neurologically handicapped. The program should strive for balance between the federal, state, and local levels of government in a comprehensive statewide delivery system. The state council should use their legislature as the instrument to gain this balance. The council should concern itself with a total program necessary to serve all neurologically handicapped children and adults.

Wherever a dispute arises between forces serving community programs and forces serving state sponsored services, the council should seek to balance the forces so that as near as possible one legislative program enhancing and interrelating both community and institutional programs can be presented to the legislator.

State councils should interrelate to assist the federal government in carrying out the Developmental Disabilities Act. Perhaps under the National Association of Coordinators of State Programs for the Mentally Retarded, or some other national association of state people, state councils, along with their state administration, should join together on a regional basis to serve those with special handicaps, and those professionals who serve the handicapped.

APPENDIX A

QUESTIONS AND ANSWERS WHICH CONCERN DEVELOPMENTAL DISABILITIES SERVICE ACT COUNCILS

The following was taken from the question and answer period at the National Developmental Disabilities Conference:

Should the funding be categorical as related to a specific handicapping condition, or should it be designated for the Developmental Disabilities?

Legislators present felt the block grant for developmental disabilities was best. Senator Dean felt that the Developmental Disabilities Service Act funding was categorical in nature and should remain that way.

Is it a good thing to have an umbrella organization for the delivery of services to the handicapped?

California has this plan but has found difficulty in: (1) acceptance, (2) working together, (3) matching and qualifying for federal funding. There is merit in having several different agencies coordinating and planning together to get the total job done. It's harder for the legislature to put the lid on several agencies than it is on one single agency.

How does the legislature do program evaluation?

The legislatures are giving more attention to accountability in the expenditure of funds. Several state legislatures have a legislative auditor to make sure the money was spent for what it was allocated for. Legislatures also are passing administrative procedures acts to scrutinize rules, regulations and programs of the several agencies of state and local government who carry out programs.

What should be the role of the State Advisory Council for the Developmental Disabilities Service Act?

The committee should have several functions to perform:

1. It should be an advisory committee to the several agencies of government, the governor and the legislature in recommending programs to adequately serve the handicapped.
2. It should serve a planning function to ascertain what is the best system to serve all handicapped children and adults and to recommend who should do it.
3. It should serve in a coordinating role to interrelate all agencies in the statewide delivery system of services to prevent duplication of services.
4. It should serve a legislative function recommending adequate budget and delineation of program to serve the handicapped.

How do you get the passive legislator to learn what developmental disabilities is all about?

Personal contact by those who know and care–preferably by someone whom the legislator knows and respects. Personal letters, unlike any other letter written on the same subject are also good. Invite the legislator to sponsor legislation embraced by a large group of parents.

Part VI
Special Services

Editor's Notes

The Developmental Disabilities Act specifies a list of 16 fundable services. The obvious intent of the architects of the Act was to permit the broadest possible interpretation of the uses to which grant funds might be put in order to offer state program officials the widest possible latitude in filling existing and future gaps in services to the developmentally disabled.

Without doubt, residential programming for the developmentally disabled has received more public attention and has stirred more interest and controversy over the past few years than any other service area specified in the Act. During this period, millions of words have been written about the deplorable conditions which exist in public and private institutions for the mentally retarded, and dozens of plans for solving these problems have been put forth. Yet, despite encouraging signs of progress in some states, the Nation still faces a mounting crisis in the provision of residential services.

The papers prepared by Elsie D. Helsel and Earl C. Butterfield offer valuable insights into the tangled problems which face residential institutions and suggest several approaches to reforming the present 24 hour care delivery system. Helsel outlines a course of action for state DDSA advisory councils to follow in dealing with what she terms the councils' "top service priority"–i.e. establishing appropriate and adequate community-based alternatives for long-term care of the developmentally disabled. She suggests some of the dilemmas Councils will have to face in approaching this task, delineates the necessary elements in an effective long term care system and discusses alternative components of a well-rounded residential program. The author also touches on the need for a back-up system of protective services and describes a model case management, protective-advocacy system currently being developed in Ohio. She closes her paper with a brief review of some of the sources of federal aid available for constructing and operating long term care facilities for the developmentally disabled.

Butterfield argues that little use has been made of research as a tool for improving residential programming. He sees the development of accreditation standards as a hopeful precursor of change but warns that the current JCAH/ACFMR emphasis on process or outcome measures in its surveys of residential facilities must be maintained. Court intervention as represented by the recent decision in the Alabama "right to treatment case" is also viewed by the author as "an important stimulus for reforming institutional services to the mentally retarded and other developmentally disabled people." Butterfield concludes by calling for more and better research studies, more effective management and in-service training, application of accreditation standards and further court actions.

The second, and often overlooked, component of the Developmental Disabilities Act is the University Affiliated Facilities (UAF) program. Authorized under Title II of P.L. 91-517, the some 35 UAF's, which are currently in various stages of planning and operation, collectively possess a vast reservoir of talent and expertise which promises to serve as an invaluable back-up system to service delivery agencies. Julius S. Cohen discusses developments leading up to the establishment of the University Affiliated Facilities program and reviews the present activities of UAF's in the areas of training, technical assistance, outreach, service and consultation, service to state DDSA councils and research. He ends with a few brief comments on the emerging role of the UAF program.*

At least two of the services specified in the Act have only been added to the lexicon of developmental disability planners in recent years—transportation and protective and other social and sociolegal services. For this reason, the Conference planners felt that papers on these subjects would help state DDSA council members and staff appreciate some of the challenges and opportunities presented by these two areas of service.

The unique problems involved in transporting the developmentally disabled are discussed in a paper by William J. Bean. He divides the problems into two major areas: mobility limitations of the physically handicapped and transportation problems of mentally retarded persons. Particular attention is given to reviewing the findings of a recent report by the President's Committee on Mental Retardation entitled, *Transportation of the Mentally Retarded.** The author closes with a commentary on some of the public policy issues raised by the recent debate over making transportation facilities accessible to handicapped persons.

Keith A. Yelinek stresses the fact that the emerging recognition of the need for protective services is a direct offshot of the growing number of developmentally disabled persons living in the community. He discusses the legal underpinnings for the three types of guardianship plans generally available (guardian of

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*In conjunction with the National Conference, the Division of Developmental Disabilities also published a descriptive brochure concerning the UAF program. Free copies of the brochure, entitled *University Affiliated Facilities: An Overview* are available by writing the UAF Branch, Division of Developmental Disabilities, RSA, SRS, Department of Health, Education and Welfare, 330 "C" Street S.W., Washington, D.C. 20201.

**Transportation of the Mentally Retarded*, President's Committee on Mental Retardation, June 1972. Prepared under contract by Harold F. Wise Associated, Washington, D.C.

the person, guardian of property and guardian of both the person and the estate) and concludes that guardianship laws in the United States are primarily directed toward protecting property rather than safeguarding the rights of the individual. As far as nonlegal forms of protective services are concerned, the author discusses the recent development of case management and personal advocacy systems indicating that such approaches will play an important future role in a total protective services system.

Long Term Care Services for the Developmentally Disabled

Elsie D. Helsel

ESSENTIALS AND ALTERNATIVES

Introduction

The development of appropriate and acceptable community based alternatives for long term care for the developmentally disabled is probably the top service priority on Developmental Disabilities Councils' wish lists this season.

However, the pay from wish list to implementation is fraught with more booby traps than a mine field in a war zone. Many problems in this area are not even recognized, yet alone defined. Hard experiential data based on careful research is almost completely lacking. The problem is not only one of not having answers. At this point in time, many groups rushing into the operation of small group homes don't even ask the right questions!

In addition, no one seems to be taking a leadership role in collecting, collating, evaluating and disseminating the little bit of experiential knowledge that we are beginning to accumulate.

Someone has said we have momentum without rationales. We have initiatives without tested models. We have starry-eyed well-meaning enthusiasm without direction. We have workshop after workshop that starts from scratch to reinvent the wheel and ends up recommending another survey or study.

So What Are Developmental Disabilities Councils To Do

Developmental Disabilities Councils charged with developing comprehensive plans for a State, including long term care plans, can start by:

1. Developing a philosophy and rationale for their State in keeping with reality and their resources;
2. Identifying the issues and problems – especially those that have surfaced from the long term care efforts of others;
3. Defining the basic elements of long term care and the population to be served;

4. Inventorying the alternatives available, the resources, and identifying unmet needs;
5. Setting objectives and realistic time schedules;
6. Evaluating and redirecting efforts and resources as needed.

Philosophy, Principles, Rationales

Before embarking on a long term care plan, DDA Councils must be honest with themselves and make some hard decisions. When they embrace high sounding concepts such as "normalization principles," "developmental models" and "community based alternatives," do they mean these concepts to apply to all the developmentally disabled who need them, or only to the chosen few who "adjust well in the community," "have hopeful potential for workshop placement," "are ambulatory," "won't cost you much," and "are reimbursable under a federal program."

Such decisions make a tremendous difference in how you go about planning, what role you assign to your present institutions and what kinds of community alternatives you develop.

If some of our developmentally disabled citizens are more equal than others – then DDA Councils should be honest and say so.

This paper is based on the assumption that every human life is valuable; everyone is capable of growth and development throughout life; the principles of normalization apply to everyone; everyone can live in a community facility and no one should be denied any appropriate program because it costs too much or his potential is too limited.

If we accept the developmental model as an appropriate one for long term care services, then we will not tolerate care that is merely custodial or care that is dehumanizing in any residential facility from the smallest of group homes to the largest of institutions.

Goals for residential programming based on the developmental model will be designed to increase the resident's control over his environment, increase the complexity of his behavior, and maximize his human qualities.

One strategy for maximizing human qualities is the normalization principle of Nirje[1] as set forth in the PCMR publication *Changing Patterns in Residential Care*. This approach requires that the developmentally disabled person have an environment and a life style that is as much like a normal one as possible. His living arrangements will therefore be homelike and his daily routines and life style will follow that of his normal peers insofar as his disability will permit. (For a detailed discussion of the implications of the developmental model and the normalization principle see the NARC publications: "Residential Programming for the Mentally Retarded Persons" Vols. I-IV.[15]

If we accept the principle that, with appropriate modification and adjustments, everyone can live in community based facilities, then the role of the institution must be redefined. It can no longer be a repository for those who have for one reason or another been rejected as non-feasible for programming. This is particularly true of the nonambulatory who are consigned to institutions. There is now ample evidence that the numbers of individuals who are truly bedfast–those for whom out-of-bed activity is a threat to life–is very small. We have created vast wards of bedfast individuals through mismanagement. Already developed are techniques and supportive equipment, which when properly utilized, would virtually eliminate the need for bedfast wards either in institutions or in nursing homes in the community. A curriculum has been developed for training contact care personnel in these techniques and procedures (UCPA's Mini-Team Project – Report in preparation[13]).

There is also ample evidence that even severely and profoundly retarded individuals can respond to training programs and can make progress toward developmental goals. Such evidence should therefore suggest that institutions become training centers–especially for those who require sophisticated and specialized training programs. Institutions should be the leaders in research and in demonstrating new procedures and techniques for maximizing human potential. They should take their place as important components in a comprehensive community services system. They should certainly not serve as repositories for rejects.

Issues and No Answers

Although most planners, administrators, professionals and parents will quickly give assent to the foregoing assumptions and principles, when it comes time to make hard decisions on problems of implementation, consensus breaks down and many unanswered, and, perhaps at this stage of our knowledge, unanswerable questions rise to block positive, concerted action.

Vested interests, fears, rationalizations, attitudinal biases, preconceived rigidities, labor practices and capital investments get in the way of trying to work out plans for long term care and services which best serve the developmentally disabled individual and his family, take into account some of their decisions and wishes, and permit them some alternatives from which to choose.

Despite the complexity of the problem, however, we must seek answers, imperfect though they may be, to such thorny questions as:

1. How do you deploy funds in order to turn the system around and provide community alternatives for residential care while at the same time upgrading care and services in the present institutional system?
2. Who should live in community based homes? Everyone or only the moderately retarded ambulatory?
3. Should anyone stay throughout their lifetime in an institution or should all placements be time limited for training purposes only?
4. Is it possible and financially feasible to provide care in large multipurpose institutions that is not dehumanizing?
5. Should programs in residential facilities (community or institutional) be self-contained or should residents go out into the community for service programs?
6. Can the UCP Mini-Team Cross-Modality approach for out-of-bed care be implemented on a wide scale in order to eliminate bedfast wards?
7. If a decision is made to go all out for small community-based residential facilities what do you do with the multi-million dollar investment in old buildings in our present institutions?

8. How can you carry on research if you don't have a large controllable population?

9. How can you offer specialized services if your population is small or dispersed?

10. As large institutions are reduced in size, what do you do about the resultant labor problems? How do you deal with the civil service and seniority requirements of state systems and labor unions?

11. How small a group home can be operated from a financially feasible point of view? Is there a size below which we must always think in terms of core support?

12. Should you tell residents of an area in which you plan to place a small group home about your intentions or should you just move in?

13. Are some types of residential areas easier to penetrate than others?

14. How do you answer parents' perfectly valid questions concerning the safety of their sons and daughters in small group homes—particularly parents who have chosen institutionalization as a way of guaranteeing a lifetime of protection for their sons and daughters?

15. If dependent individuals are placed out in the community who will be responsible and accountable for monitoring their care and day to day activities over a lifetime?

16. Who will monitor the monitors to see that human and civil rights are not abridged?

These are just a few of the questions that must be addressed if we are to provide a continuum of residential services for all of the developmentally disabled who need them.

ESSENTIAL ELEMENTS IN A LONG TERM CARE PROGRAM

Long term care means more than a place to live—it includes all of the ramifications of meeting the lifetime service needs of those who cannot live independently. In this paper, we are trying to focus attention on that segment of the developmentally disabled population that cannot, even with the best treatment, educational, and vocational training services make it on their own in society. The expectation is that they will never be able to maintain themselves independently. They will need help in managing themselves and/or their affairs throughout their lives.

Formerly they and their families had but one alternative for long term care—Institutions for the Feeble-Minded and Epileptic. Now at long last, alternatives are being developed for them in the community.

It should be borne in mind that this group will include not just the mentally retarded but also those so severely physically handicapped or with such seizure problems that they cannot live independently.

Long term care includes, at the very least, the following essential elements:

1. Alternatives and choices for suitable living arrangements.

2. Appropriate day to day programs of activity or work that will enable the individual to develop his potential and live, with dignity, a full and

satisfying life.

3. Protective advocacy and monitoring safeguards which check regularly not only on the health hazards and physical safety of the residents but on the adequacy of their programs as needs change over a lifetime. Such a lifelong monitoring system requires some provision for follow-along services. Some of the mechanisms are protective services, personal advocacy services, accreditation procedures and life safety codes.

4. An adequate financial base of on-going support for long term care services.

ALTERNATIVES FOR LONG TERM CARE

Group Homes

Of all of the community based alternatives for living arrangements, parents and professionals alike seem most turned on by the potential of small group homes. To date this arrangement seems to be the most acceptable and to hold the best possibility of fulfilling "normalization" expectations.

Group homes are loosely defined as "small" if they house fewer than 20 and "large" if they have 20 to 200.

The push into small group homes is coming from two primary directions: State governmental officials responsible for MR and DD programs who see them as a way out of some of their problems and dilemmas; and parents who have never accepted institutionalization as an alternative. The parents involved are frequently the same ones who sparked the parent movement for the development of community services in the early 50's. They know how to get things done. What they need are sound guidelines.

Some of the questions to which both groups need answers are:

Client Groupings

1. Who will live in the home? What degrees of retardation, kinds and frequency of seizures, kinds of mobility problems can be accommodated?

2. What mixes of the above groups or mixes with other groups such as college students, veterans, elderly, and other handicapped will work?

3. How and who will do the selecting of the people who will reside in the home?

Program Needs

4. Depending on the group selected, what will be their needs for care, supervision, management and day to day programming?

5. How will the program needs be met? Within the facility or externally by community services?

Staff

6. What staff will be needed and how will the staff be trained? Should institutional staff be retrained and moved out into community homes?

Attitudes

7. How do you select the location for the home? Are some residential areas more accepting than others?

8. How do you deal with community attitudes so that the group home is accepted? Do you have an advance public relations campaign or do you just move in?

9. How do you deal with parental attitudes so they will use the home and/or will not resist moving their sons or daughters out of an institution into the home?

Protective Services

10. How do you provide for accountable monitoring so that the care and program remains appropriate throughout the lifetime of individuals?

11. How do you protect against underutilization because of parental fears?

12. How do you assure that monitoring services will not overprotect? How do you insure that individuals have the opportunity to make decisions affecting their lives to the degree that they are able?

13. How do you provide for protection of civil and human rights?

Zoning–Codes

14. How do you approach zoning problems? What strategies work best? What resources are available and appropriate as problems arise?

15. How do you approach the problems of building codes and health and safety codes? What strategies are available here? What resources exist for guidance?

Costs and Funding

16. Are there any hard data available on the minimum numbers in a home to assure financial feasibility of the operation?

17. What hard data are available on the cost of operating small group homes?

18. What funding resources–both federal and state–are available for ongoing operating costs?

19. What federal or state resources are available for funding for construction, remodeling, and purchase?

20. Is any information available on costs for remodeling versus costs for new construction?

21. For what types of facilities is accreditation available?

Some of these questions have answers. Some have partial answers. Some have no answers. What is needed now is a gathering together and strategic analysis of what works in the placement and operation of group homes and what doesn't. This information could then be published in a Handbook for Professionals and Parents who are planning to start group homes. In the meantime, a good rule of thumb is to find someone who is operating a home similar to the one planned, to go visit the home and talk with the persons responsible, to observe the types of clients and the day to day operation. Lists of such homes are being prepared by the National Association of Private Residential Facilities for the Mentally Retarded. This new national group has other informational materials available and, at the conclusion of their present project, will be publishing a Directory of Private Residential Facilities. [Manfred Hall, Executive Director, National Association of Private Residential Facilities for the Mentally

Retarded, 1411 Jefferson Davis Highway, Arlington, Virginia 22202.[9]] The Rehabilitation Services Administration has also funded a project to evaluate group home programs. [Dr. Gail O'Connor, Research Director, Rehabilitation Research and Training Center in Mental Retardation, College of Education, University of Oregon, Eugene, Oregon, 97403.[10]]

Institutions

No one takes satisfaction in poor care—least of all superintendents of institutions who struggle daily with problems of inadequate budgets, insufficient staff, old buildings, large client numbers and an apathetic public except at election time or when there is a tragedy or a scandal. The issue is not poor care in an institution versus good care in the community—the issue is an appropriate continuum of care for all individuals who need it.

At this point in time despite all the histrionics and hand wringing institutions are a necessity. We simply do not have alternative placements for the 200,000 plus people who are in institutions at the present time. The problem confronting us is how to help these institutions provide care and programs that are developmental using whatever techniques and strategies are productive.

There are several activities underway that should be helpful. Standards have been developed by the Accreditation Council for Facilities for the Mentally Retarded and a voluntary accreditation procedure is now available. The Standards were developed by this Council over a period of four years. Present Council members are: American Academy of Pediatrics, American Association for Mental Deficiency, American Nurses Association, American Psychiatric Association, American Psychological Association, National Association for Retarded Children and United Cerebral Palsy Associations, Inc. State officials, concerned superintendents and parents now have some guidelines and yardsticks to use in gaining increased public and legislative support. The Standards are appropriate for residential facilities of any size.

Federal laws and regulations are beginning to consider requiring that states that wish to participate in programs with federal funds must meet Accreditation Standards. Federal programs such as Medicaid, Social Services, Title I of the Elementary and Secondary Education Act are becoming increasingly available to state institutions to help them in upgrading services. In the 92nd Congress, several pieces of legislation were introduced to assist institutions and to help states meet accreditation standards. Also several bills were introduced to assist with the education and training of severely and profoundly retarded residents.

Certainly institutions have problems. Certainly the role of the institution must change as it takes its place as one of the components of a continuum of community services. Whether institutions will survive depends a great deal on whether they can shift to a new role and how productively they can fill this role.

Regional Residential Centers

Regional residential centers which 10 years ago were thought to represent the millennium arriving, have for the most part been duplications in microcosm of large institutions. They do have the advantages of reduced size and of being community based. There residents usually participate in community services that are appropriate. Some centers offer day training programs for community residents so they do become part of the community continuum of program services. For the most part, however, care is still congregate and hardly in keeping with the normalization principle.

Foster Homes

More and more states are turning to foster home placements for adults as well as children as an alternative to institutional placement. Where the state has a good system of home-finding and adequate social case work backup, this has been a reasonably good alternative and less costly than institutional care. Where parents have institutionalized children early in order to insure a safe protective environment, and where these children have now been placed out in foster home care, the use of foster homes has posed some serious adjustment problems.

One good resource for basic data on costs, staffing and the realities of foster home placement for adults is the 5 year project of the New York Service for the Orthopedically Handicapped (Nash[7]). This project showed clearly that foster home placement is an effective alternative for care for even severely physically handicapped adults so long as a good social case work support system is available.

Adoptive Homes

As attitudes toward handicapped children change, adoption of such children becomes an increasingly used resource for long term care. Not only does it obviously provide a much more normalizing and developmental environment for the child but a recent study by the Columbia School of Social Work[1] shows it to be a much less costly way to provide care–roughly one-fifth the cost of foster care according to the study.

Nursing Homes

For severely disabled individuals needing nursing care, placement in nursing homes has been reasonably adequate so long as young adults are not placed singly in homes and so long as programs by the day are provided outside the nursing homes. With the availability of federal funds through medicaid, nursing home placements have, unfortunately, sometimes been used inappropriately.

UCPA, Inc., has for several years had some affiliates using nursing home placements to good advantage. Some affiliates have been able to get private sources to build nursing homes from which care could be purchased. Where care and program are individualized and the affiliate has acted as an advocate when problems arose, such placements have been reasonably good and meaningful relationships have developed between the elderly and the young residents in such facilities.

Hostels

Both New York (Department of Mental Hygiene[6]) and Michigan (The Record[12]) have state funded hostel programs which provide partial funding for construction and ongoing maintenance. The term "hostel" seems to include any type of supervised living arrangements from apartment living to group homes of all sizes.

Contracted Services

Some states are now contracting for residential services with private corporations. Although it is possible to provide adequate residential services in this manner, unless the state also has a protective advocacy system for ongoing monitoring of such placements, serious problems can and do arise. One state which is presently using such a system has just had to close down one of the contracted homes because of the unexplained death of a young mongoloid boy at the hands of another resident. An investigation disclosed a scandalous situation where five or six previous questionable deaths had occurred in the same home. Contracted services without safeguards can result in care that is just as bad as the very worst of our institutions. We can be faced with hundreds of small snakepits if adequate safeguards are not required.

FOKUS

In Sweden an organization, FOKUS, has taken responsibility for providing the supportive service necessary for severely physically handicapped persons who want to live independently in the community. FOKUS helps such individuals plan and secure living arrangements, dress, eat, move about, run an apartment, and work—but only to the extent they believe is necessary and only on call from the handicapped individual. In the United States, the only alternative for such severely disabled individuals other than their own home would be a very skilled nursing home or an institution. Slides are available to show how even exceedingly handicapped individuals can live independently in an apartment modified architecturally to suit their needs. This apartment is located near a complex of community services which provide for the material, social, intellectual and work needs of the occupants. Occupants call for help only as needed, for example for getting out of bed, for getting bathed and dressed in the morning or for being put to bed at night. Such an arrangement could readily be used with epileptic persons with uncontrolled seizures who need only occasional supervision or help.

Public Housing for the Elderly and Handicapped – Other HUD Programs

Two communities, Toledo and Seattle, have on-going public housing programs for the elderly and handicapped. The future possibilities of such mixes are limited only by our own ingenuity—or lack of it. Several states and communities are exploring the use of HUD funds to provide non-institutional housing for adult developmentally disabled.

Apartment Buildings

ENCOR in Nebraska is providing some excellent experiential information for this type of living arrangement. Although at this time most of the residents are ambulatory and only mildly to moderately retarded, the potential for all kinds of developmentally disabled individuals is very exciting indeed. Using the ENCOR approach with appropriate supervision and backup support and trying different mixes of normal families, college students, mentally retarded, physically handicapped and epileptic individuals the possibilities for developing appropriate patterns for residential living in communities seems endless.

Hotels and Motels

Some experiential knowledge is available in this area. Motel 66 in California and the Hotel Experience of the Division of Mental Retardation in Illinois are two illustrations of using this type of facility for residential care. Once again the key not only to success but to the avoidance of catastrophe is an accountable monitoring service which will watchdog the care and programs of the residents.

Own Home

Some information is available from places like Connecticut where one of the regional centers took responsibility for setting up a small group home using the personal home of a retarded middle aged woman whose family had died. With a responsible agency and a backup monitoring system this certainly provides an acceptable solution for long term care. It also has the advantage of keeping out of tangles with zoning ordinances and code regulations if the number of unrelated residents is kept to four.

Summary

In summary there seem to be plenty of options for the development [illegible] alternatives for community living. Additional resource pieces that have helpful information are: *"Residential Needs of Severely Physically Handicapped Non-Retarded Children and Young Adults in New York State* (Fenton[3]); Residential Care Needs: *Handicapped Persons Pilot Project,* California[4]; and the chapter on residential services in Vol. III of the book, *Mental Retardation* (Helsel[5]). Two excellent publications that include up to the minute reports on current activities in the area of long term care and services are: *The Record*[13] publication of the National Association for Retarded Children's Residential Service Committee and *New Directions,* a monthly newsletter of the National Association of Coordinators of State Programs for the Mentally Retarded, Inc.[8]

PROTECTIVE ADVOCACY

Of the basic essentials for long term care, three are fairly well understood and usually included in long term care plans– 1) alternatives for living, 2) day to day programs, and 3) funding resources.

One absolutely essential component–a protective advocacy service–is apt to be overlooked. Or, as has been the case with institutional placements, it is apt to be considered unnecessary because the superintendent or the operator of the facility can provide protective advocacy. Such, unfortunately, is not usually the case. Especially when dependent individuals are involved, some type of monitoring system must be built in. Someone outside of the service delivery agency or system must be responsible and held accountable under law for the well being of the dependent developmentally disabled and for the adequacy of programs.

In response to the recognition of this need and also in response to the suits in court to insure protection of civil and human rights, a new program component of long term care with new structures and new patterns of delivery of service is emerging. Several models are being used and at this point in time no one model seems to be *the* way to provide protective advocacy service.

Some of the elements that seem to be essential in any model, however, include:

1. Clear separation of the service delivery function from the monitoring, protecting and advocating function.
2. Responsibility and accountability assigned by law to an agency and/or an individual outside the service system and with no conflict of interest.
3. Provision for varying levels of help with decision-making from minimal counseling through varying degrees of case management to maximal full guardianship.
4. Protection of civil and human rights with regard for due process.
5. Protection of human rights with due regard for confidentiality of records and right to privacy that is in the best interest of the client.
6. Mechanism for follow-along tracking with due regard for civil and human rights.
7. Provision for personalizing and individualizing the advocacy service through a program of personal advocacy.

Ohio's Case Management Protective-Advocacy System

In Ohio where a case management protective services system went into effect under law July 1, 1972, the various responsibilities are defined and assigned as follows:

1. Case Management – Case Management services provide or see that the service is provided: intake, counseling, diagnosis and evaluation, prescriptive programming, referral to appropriate services, regular assessment of outcomes and modification of program prescriptions. In addition such a service has the capability of responding on a 24-hour, seven days a week basis to client needs.

2. Protective Service – A Protective Service is a monitoring, tracking, appraising, counseling, and advocating service for individuals who need help in managing themselves and/or their affairs.

3. Personal Advocacy Service – A service in which an individual assumes responsibilities for looking after, as if they were his own, the interests, rights, and personal needs of a developmentally disabled individual.

Other states have different ways of defining and assigning responsibilities. The important fact to note here is that a long term care program *must* address the problem of seeing to it that all of the responsibilities are assigned and that someone is accountable.

Ohio DDA Councils Involvement in Long Term Care

The Ohio Developmental Disabilities Planning and Advisory Council designated as its top priority a residential model of services which included protective services, case management, personal advocacy and a commitment to the development of community alternatives for long term care.

In order to get this project off the ground funds were given to a consortium of Ohio Association for Retarded Children, Epilepsy Foundation of America, and United Cerebral Palsy of Ohio to conduct a residential seminar which would involve as participants state leaders, state administrators, professionals in the field, volunteers and the handicapped themselves. The seminar was to focus attention on the program needs in the residential services area and to lay out some philosophical positions and guidelines for the State of Ohio to take with regard to residential services.

In addition to drafting 12 working assumptions for a state residential services program, the attendees at the conference passed a resolution recommending that over the next 10 years the present institutional system be phased out; that a system of community based residential units be developed; and that any monies earmarked for construction for institutions be reallocated to construction of such units. The conference further recommended that funds be requested from the DDA Council for a Residential Planning Project to develop a state plan which would be a compilation and collation of 10 grassroots district plans developed by reactivated citizens committees in each of the 10 districts of Ohio.

Governor John J. Gilligan addressed the closing session of the seminar and endorsed the recommendations. In order to get the citizens committees reactivated and the effort rolling at the grassroots, DDA provided funds for the hiring of a State Coordinator. The DDA Council also agreed to fund the residential planning project providing the consortium of three agencies would incorporate in order to provide a sound administrative structure for the supervision and carrying out of the project. At time of this writing the groups have incorporated under the name of Ohio Developmental Disabilities Incorporated, have elected officers, have appointed board members, and are in the process of hiring staff.

Backing up this effort the Developmental Disabilities Council has also provided funds to the Division of Developmental Disabilities to expand its case management system so that the entire state is covered. This system provides in each of the 10 districts of Ohio, a District Office which is the point of referral for all individuals and families who need or think they need residential or other services. After intake and evaluation every effort will be made to find a suitable residential placement in the community. If this is not possible the individual may enter the institutional system. All entries and departures from the institutional system will henceforth be made through the district offices. Some funding for residential placements is already available through family care funds in the Division's budget. To provide more adequate funding for this endeavor, the Division of Mental Retardation and Developmental Disabilities will include a line item in its next years' budget for additional funds for purchase of residential care. The Governor has already indicated his support of this request.

As individuals are placed either in community placements or in the institution, a referral will be made to the protective service of the state authorized under House Bill 290. This bill provides for ongoing follow-along monitoring services to check regularly on individuals in its care and report in writing at least annually to the Director of the Division of Mental Retardation and Developmental Disabilities on the condition of the individual, his response to the program, and the appropriateness of the placement. Also authorized under this bill is a public guardianship program for those individuals who are felt to need this amount of supervision and control. Parents can apply for this guardianship while they are living or ask for it as a successor guardianship in their wills. A computerized tracking system will be used to follow individuals in the protective service so that they do not get lost. DDA funds have already been allocated to develop the system.

The protective system has been operational since July 1, 1972 with 12 workers plus an administrator authorized. Although this program is budgeted by the Division of Mental Retardation and Developmental Disabilities, some DDA funds have been assigned so that this program can be expanded as rapidly as the Division is able to hire and train workers. Workers are inservice trained in a training course conducted by the University Affiliated Facility in Columbus, the Nisonger Center. The training program is funded with DDA funds.

In the meantime, with DDA Council "nudging," the Division of Mental Retardation and Developmental Disabilities and the Department of Welfare have negotiated a contract using social services funds to hire 100 additional protective service workers and 100 additional case managers.

As a watchdog on this state operated protective service, the DDA Council is also funding a project for the development of a statewide personal advocacy system. Funds have been assigned to the incorporated consortium to hire a statewide personal advocacy coordinator to work with the reactivated citizen's committees and with the voluntary agencies at the local level in the development of this system. Once again DDA funds have been allocated to the University Affiliated Facility in Columbus to train the personal advocacy workers.

Thus DDA funds have been used to help put in place a resource. Salaries of the state citizen's committee coordinator and the state personal advocacy coordinator will be ongoing commitments on the part of the DDA Council. DDA Council funds will also provide ongoing training support for these programs. Initially some project monies will be used to help agencies get their personal advocacy projects off the ground. However, in the long run these programs will be expected to be staffed by the agencies themselves with volunteers serving as advocates.

PATTERNS OF FEDERAL SUPPORT

Long term care for a developmentally disabled individual is expensive. The cost of institutional care over a lifetime has been estimated at somewhere between $300,000 to $500,000. At present no type of help or catastrophic insurance is available to help families meet such astronomical costs.

Recent acts of Congress have, however, provided bits and pieces of help with some of the elements.

Funds for Construction of Living Arrangements

In addition to DDA funds there are three major resources for construction funds for long term care facilities:

1. Housing and Urban Development funds under Section 231,232, and 236 of the National Housing Act of 1959 are available for construction, rehabilitation and equipping of long term care facilities such as nursing homes and ICF's.

2. Health, Education, and Welfare funds are available under the Hill-Burton Program which provides grants, loans and loan guarantees for the construction, rehabilitation and/or equipping of long term care facilities. For those living in Appalachian areas Appalachian 202 and 214 funds are also available.

3. Under Sections 502 and Section VII-A of the Small Business Act loan guarantees and direct loans are available from the Small Business Administration to construct, expand, rehabilitate and/or operate long term care facilities.

Federal Funds for Ongoing Operating Costs

Resources for operating costs of long term care can come from many sources. The primary funding resources are: Medicaid, Social Security, third party payments including health insurance, patient or family payments, local tax levies, and general fund appropriations.

Under the Social Security titles there are several possible funding resources. For those individuals in categorical assistance programs or living in states where the medically indigent are covered, Medicaid funds are available for care in skilled nursing homes or in intermediate care facilities. Under PL 92-223 federal matching under Medicaid became available for care of the mentally retarded in public institutions which qualify as ICF's provided that health or rehabilitative services were available and provided that the resident was receiving active treatment. In addition, each such eligible person in a public institution or nursing home or ICF who is getting Medicaid funds also qualifies for up to $25 per month for incidental expenses.

Aid for the Permanently and Totally Disabled

The recently passed amendments to the Social Security Act contain a real breakthrough for support of ongoing costs of care for disabled individuals. Beginning in January, 1974 the Aid for the Permanently and Totally Disabled program will be "federalized," and administered by the Social Security Administration under federal criteria and guidelines. At this time there will be federal basic support for disabled individuals of $130 per month. In addition, the disallowances have been liberalized and individuals may keep up to $20 per month from any resource. They may also keep up to $65 per month of earned income and half of any additional earned income up to the maximum allowed. The $130 per month is reduced by one-third if the individual remains at home. The breakthrough insofar as long term care is concerned is that parental liability for individuals above the age of 18 will be removed. Not only will every disabled individual above the age of 18 qualify for support funds, but eligibility for categorical assistance programs usually implies eligibility for Medicaid to cover health costs and eligibility for social service programs including protective services, information and referral services, homemaker services, nutrition services, adult education services, training and employment services, chore services, and a whole host of other benefits. States are expected to add to these federal funds in order to provide an adequate support base for appropriate long term care. [*Editor's Note:* See also discussion of the provisions of the Social Security Amendments of 1972 (P.L. 92-603) in Jerry Turem's paper entitled "Services Under Titles IV and XVI."

Social Security Benefits Under Title II

Childhood Benefits (formerly Adults Disabled in Childhood). If parents are covered by social security or railroad retirement, at the time of retirement of the parent, the disabled son or daughter is eligible for an amount equal to one-half of the parent's social security benefit. At death of the parent the disabled individual is eligible for three-quarters of the benefits of the parent. After a 24-month initial period beneficiaries of Childhood Benefits become eligible for Medicare. As basic social security benefits increase, therefore, so will children's benefits.

Disability Benefits. Disabled workers in sheltered workshops can qualify for disability benefits on their own earnings. The amount of work needed to qualify depends on the age at which the individual becomes disabled. If disability occurs before the age of 21 the individual must have credit for 1½ years of work in the 3-year period ending when application is made. When an individual becomes eligible for disability benefits, after an initial 24-month waiting period, he also becomes eligible for Medicare.

Federal Funding for Day to Day Program

Since other sections of this Conference are addressing indepth the funding resources for programming, this paper will merely list some of the resources: Titles I, III and VI of the Elementary and Secondary Education Act; the Rehabilitation Act; Titles I, IV, X, XIV, and XVI of the Social Security Act, Comprehensive Health Planning, Vocational Education Act, the Adult Basic Education Act, in addition to the Developmental Disabilities Act.

Protective Services

The new Social Security Amendments contain helpful provisions for social services–including protective services for all recipients of categorical (welfare) programs. Since permanently and totally disabled individuals over the age of 18 will now qualify for aid for the disabled if they have no financial resources of their own, they become eligible for social services. In addition, there is a special priority coverage with open-ended funding (up to the limit given to the state on the basis of its population) for children and adults who are mentally retarded. Although there was some confusion and misunderstanding on the part of some members of Congress concerning the use of the term "mentally retarded" rather than "developmentally disabled" Congressman Mills has assured us that it was the intent of the Conference Committee to involve them. Congressman Mills in a speech on the Floor of the House concerning the definition of "mentally retarded" explained the intent of Congress thusly:

> "The term 'mentally retarded' does not apply to a specific ailment or disability as known by the medical profession. It normally describes persons–and this is our intention–who, because of neurological or other causes at birth or in early childhood have increased difficulties in their social function." (Congressional Record[2])

Hence all developmentally disabled individuals should qualify for funding for protective services from social services funds. [*Editor's Note:* See further discussion of this point in Jerry Turem's paper entitled "Services Under Titles IV and XIV."

CONCLUSIONS

As Developmental Disabilities Councils really get rolling and the individuals administering the various federal-state programs at the state level work together around specific problems, it is obvious that many new possibilities for cooperative action in the provision of comprehensive long term care programs will be found. It would seem we are limited only by our creative imaginations and our will to accomplish our goal.

There are lots of options for developing long term care services. There are few models. There is a great need for someone to assume responsibility for putting it all together.

President Nixon has asked that the large institutions be reduced in population by one-third. Those people can't just sit on curbstones. Community alternatives must be developed for them. Hopefully we will not repeat mistakes of the past. Hopefully we will not exchange Christmas in purgatory in large institutions in the country for dozens of small Christmases in purgatory in group homes in the city.

In closing the residential services seminar in Ohio, Governor Gilligan perhaps put his finger on the key to the whole problem. He said:

> "The one thing that I would insist upon, I will tell you now in response to your 12-point platform is that there be citizen participation in these programs at all levels from planning to implementation. I will say that unless we have that, we are not going to make any real or lasting progress. I don't care how the system is designed, it will have a way of slipping into a bureaucracy more concerned with the wellbeing of the people operating it than the people it serves. It's the nature of the game. Full citizen participation at all levels, at all times, is the only way we are going to make progress and the only way we are going to protect what we have achieved. (Ohio Residential Seminar, Proceedings[11])

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Factors in Planning Residential Arrangements For the Developmentally Disabled[1]

Earl Butterfield

Acknowledge with me that the developmentally disabled of this country receive inadequate care from residential facilities for the mentally retarded. There is no doubt that they do. You can see the inadequacy of our nation's main residential services for the developmentally disabled any day you choose. You can see it in the ledgers of your state's treasury. The state, which spends the most per day to provide total care for the residents of its institutions for the retarded, pays less than one-third the average required per day to receive only medical care in our nation's general hospitals. If you believe that it costs less to provide all the care required by a disabled child than it does to treat the specifically-diagnosed physical informities of people in hospitals, then you should look more directly at the problem. Examine the photographic evidence of *Christmas in Purgatory*. This document by Burton Blatt and Fred Kaplan will rend your heart as it shows you the failure of our residential facilities to help the developmentally disabled. If you believe that the frightful conditions portrayed by Blatt and Kaplan no longer exist or are not representative, go to your nearest residential facility for the retarded. Observe, if you are allowed, each living unit in the facility. Ask yourself whether the activities you see seem beneficial for the children who are participating in them. Observe their food and how it is presented to them. Determine how many residents are seen, let alone served, by the professionals who are retained by the facility and inquire about how many of those professionals are barred from practicing on the general public. Ask yourself whether what you see outrages your human sensibilities. You will answer that it does. You will be convinced that action is needed to improve residential care for the developmentally disabled.

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[1] This paper was presented and has been revised in view of its discussion at the National Conference on Services and Facilities for the Developmentally Disabled, Washington, D.C., November 16-18, 1972.

Resist the temptation to blame anyone for the deplorable conditions and lack of treatment in residential facilities for the retarded. You may have a great urge to damn and punish those who seem most immediately responsible, the administrators and employees of the facilities. They seem responsible usually only because they have remained at the scene of the crime, and they have usually done that because they recognize the size of the problem and are trying to improve the situation. Recognize at least, that powerful social and economic forces have acted for generations to mold the institutional system whose shortcomings are so readily apparent today. The eugenic movement and the great depression, to name only two social movements, caused many of the ills of today's residential facilities. Blaming those who now sit in positions of authority for the consequences of such forces, which acted before their tenure, is unproductive at best. At worst, it results in defensive maneuvers that further reduce the effectiveness of those very people who must do most of the work to improve residential services. Moreover, those people who are now in the vanguard of reformers, more often than not, draw their inspiration and proposed innovations from experiences in existing facilities for the retarded.

Do not succumb to the belief that nothing can be done. It is too ready an excuse to conclude that because well-meaning people have failed for generations to find ways to provide humane care and habilitating services for the developmentally disabled, that you cannot now rise above the forces that have put them down. Our knowledge is greater, our resources more abundant, and the social climate more conducive to helping the afflicted than it has been for decades. Thus, some residential facilities are dramatically improving their conditions and services. The task now is to increase the number of facilities that are improving and to accelerate the pace of change.

INCREASING AND REFINING KNOWLEDGE

Some of us, and I put myself squarely in this group, believe that increasing and refining knowledge is a key to improving services for the developmentally disabled. We have sought several kinds of knowledge. For example, we documented that residential services were imperfect by showing that some facilities had more beneficial effects upon their residents than others, and that even the most beneficial programs fell short of reasonable standards of resident improvement. Thus, when IQ change is the criterion for quality service, the most remarkable improvements have been in the vicinity of 5 IQ points. The children who showed these "large" improvements generally came from such adverse preinstitutional environments that the most reasonable conclusion about why they improved was that they were removed from a bad situation, not that the institutional program was better suited to them than to children who came from more satisfactory backgrounds and showed either no increase or actually lost IQ points.

The work of Michael Klaber is an excellent example of trying to improve residential treatment by increasing and refining knowledge. Dr. Klaber examined intellectual, self-help, and happiness behaviors of carefully-matched severely retarded people in six different residential facilities. He demonstrated that those facilities which promoted residents' happiness also promoted their self-help and intellectual behaviors. One can no longer justify failing to provide educational programs on the grounds that it decreases the happiness of the retarded. Klaber also concluded that the resident-employee ratio is a useless statistic, because there is a qualitatively different kind of interaction between residents and employees in different sized groups. One employee in a group of 10 residents is better than 10 employees in a group of 100 residents. Moreover, the presence of volunteers transforms training programs for the better. Klaber's research provides many other clear guides to particular ways of improving the delivery of residential services to the developmentally disabled.

MANAGEMENT AND INSERVICE TRAINING

During the last 20 years, many researchers have gathered information which clearly shows how residential services for the developmentally disabled can be improved. Until very recently it has been difficult to justify and maintain the belief that this research contributed anything to the improvement of conditions in residential facilities for the mentally retarded, because its implications were not used. Just accumulating information had not improved residential services. The reason, some have concluded, is that conventional research reports do not reach the people who influence residential service programs. It follows that if the implications of those reports were disseminated to the proper people, they would change residential services to make them reflect research findings. The question is, who are the proper people and how should the information be conveyed to them?

The people who can influence residential services can be divided crudely into two categories: managers and service deliverers. Managers include superintendents and other administrative personnel within institutions, as well as their immediate extra-institutional superiors. Service delivery personnel are professionals such as physicians, psychologists and teachers, and technicians who are usually called aides or attendants. The technicians are far and away the largest group. Many efforts have been made to convey relevant information to both managers and delivery personnel. Managers have been invited to participate in conferences and workshops. For example, Michael Klaber, with the assistance of the Social Rehabilitation Service, convened a three day conference at which the results of his and other research on effective institutional programming was described and discussed at length. The goal was to design ways to import the implications of his research into the institutional systems of all of the United States. The Southern Regional Education Board has implemented a more formal and long-term management training program which combines all of the best features of management training employed in industry. Personnel from many institutions participate in this program. Service delivery personnel regularly participate in inservice training programs of many sorts. Practically every residential facility for the retarded has an inservice training program of substantial magnitude.

The effects of all of these efforts to change residential programs by conveying information and attitudes are negligible. Practically everyone who has tried to assess the impact of such efforts has concluded that the impact was small. The consensus is that the delivery of services depends on local tradition, and that the informal power structure of residential facilities functions to preclude innovation and change of that tradition. I believe this conclusion. I also believe that the power structure which impedes innovation and improved service is, from many vantage points, a constructive response to conditions and events in residential facilities. I do not know how much worse the conditions of residential facilities would be if these informal power structures did not arise within them. But I am certain they would be worse. The problem is to isolate the valuable functions these seemingly conservative structures perform, and to devise ways to continue to meet these functions while removing the barriers to change which the structures present. I am convinced that systematic and creative approaches to their understanding their internal structures and processes will produce orderly improvement in our residential facilities. Simply continuing the present inservice and management training routines will not. The challenge is to mount such creative and systematic efforts.

ACCREDITATION OF RESIDENTIAL FACILITIES

When I concluded that the results of research into residential programming affected that programming negligibly, I began looking for an opportunity to do something that would have a more substantial impact. I thought that opportunity had arisen when I was asked to work with the Joint Commission on the Accreditation of Hospitals to develop procedures and standards that would be used to accredit residential facilities for the mentally retarded. The work of the Joint Commission had earlier in this century revolutionized treatment and care in general hospitals, and I envisioned them doing the same for residential facilities.

All of the early indications are that the accreditation program of the Joint Commission will be a uniquely powerful force for revolutionizing residential care for the mentally retarded, at least, and perhaps for all developmentally disabled persons in this country. This probably stems in the first place from the voluntary character of the organization. Interested groups, like the American Psychiatric Association, the American Association on Mental Deficiency, and the National Association for Retarded Children, voluntarily agreed to work out mutually satisfactory standards for the evaluation of residential facilities. Large numbers of facilities are voluntarily submitting themselves to the evaluation procedure. They are even paying for it. This signals that the facilities themselves are enthusiastically in favor of changing. Without that enthusiasm, change would indeed be unlikely.

The second reason for the Joint Commission's probable success is that they have departed from the entirely structural approach they employ to evaluate general hospitals for accreditation. They rely upon measures of the process of delivering services and upon indices of the outcomes of services, as well as upon the structural features of the facility when they evaluate residential facilities for the retarded.

Let me illustrate the structural approach with an example. People often die in hospitals. An important question is whether the treatment received by patients who die contributes to their death. A hospital where it frequently does should not be accredited. The structural approach to coping with this problem is to determine whether each hospital has an established procedure for reviewing the causes of death of its patients. If it does, and if those procedures involve review by people with specific credentials, then the hospital meets the structural standard for this problem. An alternative would be to observe a sample of patients who are receiving care, and to evaluate the extent to which the process of delivering that care meets specified standards. Yet another alternative would be to survey the outcome of the treatment of patients falling into different categories, and to determine whether actual death rates meet specific standards. Hospitals in which the outcome is more often death should be denied accreditation.

Take an example more appropriate for a residential facility for the retarded. The question is whether the residents are receiving minimally acceptable special education. A structural way to answer this question is to determine whether a facility's teachers prepare lesson plans and whether those plans are appropriate for the pupils she teaches. A process way would be to observe the teacher as she works with her pupils. An outcome way would be to assess the knowledge of her pupils before and after she has taught them to see if their knowledge increases an acceptable degree.

Structural, process and outcome standards all have shortcomings. They also all have strengths. The basic problem with structural standards is that meeting them, particularly if they are relatively low standards, does not guarantee nor probably even markedly increase the likelihood that a facility's program has desirable outcomes. The basic problem with outcome standards is that specifying them is often difficult, and satisfactorily assessing outcome is more difficult and time consuming than assessing structural criteria.

The appropriate response to the various advantages and difficulties is to employ a mix of structural, process and outcome standards. Even a close reading of the Joint Commissions' statement of standards for residential facilities for the mentally retarded suggests that they do not do that. The standards document is composed almost entirely of structural statements. In fact, however, the Joint Commission does observe process and outcome during its evaluation procedure, and it weighs these observations very heavily when deciding whether to accredit a facility. This is a radical departure from previous accrediting efforts, and if this practice is maintained, I believe that the Joint Commission's accreditation procedure will continue to be a uniquely potent force to improve residential services for the retarded.

There are movements to give the accreditation procedure more formal authority. Thus, Senator Javits has introduced legislation which will tie Federal support which residential facilities receive to their accreditation. Other such efforts will be made, and judging from the history of accreditation for general hospitals, they will make it imperative for residential facilities to seek and secure accreditation. As the accrediting procedure becomes more important, the pressure to relax standards below their currently high level will grow. Those pressures are already great. I am concerned, therefore, that the process and outcome portions of the evaluation are so much less public and standardized than the structural standards. They appear, at least, more corruptible.

Many more resources were put into developing structural standards than process and outcome standards. The ratio of time and money spent on structural as compared to both process and outcome evaluation must have been in the vicinity of 100 to 1. Literally hundreds of thousands of dollars and thousands of professional hours went into the preparation of the structural standards. They were worked on by well over 200 professional persons. Less than $5,000 dollars and the limited time of only two professionals went into planning possible process and outcome measures. When, at the time it had to act, the Joint Commission was faced with the obvious discrepancy in detail and consensus concerning the three kinds of standards, it had little alternative but to publish more complete structural standards than process and outcome standards. The question about why the differential investment in the various kinds of standards remains unanswered. The answer is undoubtedly complex and many of its details surely reflect a realistic recognition of difficult problems. The fact remains that if the accreditation procedure has any weaknesses, they must lie in the procedures for evaluating process and outcome.

The opportunity to improve the evaluation of process and outcome is at hand. The work of making on-site evaluations of the facilities that have applied for accreditation has just begun. Only six have actually been visited, and eventually most of the facilities in the country will be examined. The question is whether the rare opportunity implicit in this fact can be realized. The rare opportunity is to collect truly representative and comprehensive data on the programs of residential facilities and to conduct research on how to evaluate the process of delivering residential services and the outcomes of those services while examining the facilities to determine whether they should be accredited. I see two obstacles to such an endeavor. One is the natural reluctance to acknowledge that so important a procedure as accreditation evaluation is so imperfect that it needs to be improved, and yet so robust that experimenting with it will not cause any deserving facility to miss being accredited. Overcoming this obstacle will require an act of faith based in part on the recognition that process and outcome will be evaluated, either with current techniques or improved ones. Improved ones would be better for everyone, so the faith will come when someone specifies how he will develop improved procedures while insuring that this development will not degrade our current imperfect ones. The second obstacle is to find the resources for such an effort. The fees paid for evaluations undoubtedly cannot support the expense of adding research activities to the evaluation procedure. I even question the fairness of trying to finance such an effort in this way. The obstacle must probably be surmounted by a grant from either a Federal agency or private foundation. Since the rate of evaluating residential facilities will accelerate, the time to secure such funding is slipping away.

COURT ACTION

Recent court decisions in class action suits on behalf of the retarded show that the courts have become an important stimulus for reforming institutional services to the mentally retarded and other developmentally disabled people. Despite the courts' inherent executive weakness, they have shown in such cases as *Wyatt vs. Stickney* in Alabama that they can instigate massive changes in residential services for the retarded.

From my viewpoint, the most astonishing feature of the courts' decisions in favor of institutionalized retarded people is their reliance upon research findings. I observed earlier that research findings had not had an appreciable impact upon the service programs of residential facilities for the retarded. These findings had not, for example, been used effectively in inservice training programs in residential facilities. The courts have changed this by relying explicitly upon the best interpretations of empirical studies. In the process, they have created a need for additional research whose purpose should be to determine how to best implement the broad mandates handed down by the courts. The court action in Alabama illustrates this need. The chief bases of the complaint in *Wyatt vs. Stickney* were that the physical plant was unsafe, that the facility was undermanned, and that the facility's staff had not prepared nor executed a plan for the rehabilitation of each of the residents in Partlow State School.

Documenting poor physical provisions and prescribing the cure for them seems simple. Safety and health codes are explicit, and failure to comply with them can be assessed easily. To correct substandard facilities seems to require only the appropriation of funds, because the technology for constructing and remodeling buildings is straightforward and available on the open market. But even this relatively simple part of improving residential facilities has pitfalls which are obscured by our ignorance and might undo our best effort to rehabilitate the retarded. There is first the question of what kinds of architectural arrangements are most likely to enhance the development and foster the habilitation of the developmentally disabled. Will simply renovating any particular facility's old and dilapidated buildings serve our greater goal of habilitating the retarded, or will it have only a cosmetic effect? Is the care we provide conditioned so heavily by the physical structures in which it is given that we should build relatively low cost structures so that we can afford to replace them as our understanding of curative care evolves? How shall we prepare residents and employees who have lived and worked in outmoded and inadequate facilities to care for and maintain new ones to prevent them from being turned into new horrors like some of the urban housing developments with which we have attempted to eliminate slum conditions?

Determining that a facility is understaffed is more difficult than diagnosing its physical defects, but there are some guideposts. If there are too few service personnel to cover all buildings on all shifts, then more employees are needed. But, what if all shifts are covered so that the employee to resident ratio falls in the vicinity of that recommended by the American Association on Mental Deficiency, and residents are still not receiving adequate physical and education care? Are the recommended ratios too low, as many believe, or are the employees not working efficiently and wisely? Each facility probably has a different employee/resident requirement, depending on the character of its residents, its physical layout, the number of unpaid workers it attracts, and the quality and quantity of its leadership. Neither the courts nor any other social institution may have the wisdom and resources to assess these factors well. Recognizing this, the natural human reaction is to be charitable and conservative, and to prescribe more help for the facilities with inadequate programs. This is a charitable reaction if more help is needed, but if the problem is poor utilization of available help, then this reaction may worsen the situation. At the very least, it will take funds that might be used for more relevant changes. At the worst, it will increase the problems of utilizing the abilities of the available personnel, because a facility which is using its present employees inefficiently can be reasonably expected to use more employees even less efficiently. We need solid data on the numbers and kinds of personnel required for different treatment plans for different kinds of residents.

Recognizing the absence of treatment plans for residents is simple. Providing the will and expertise to formulate and implement such plans is much more difficult. The biggest problem lies in our conception of how to do these tasks. Simply put, the conception is that an interdisciplinary team of professionals apply their various diagnostic arts to each retarded person, pool their findings, and develop an integrated plan to habilitate the individual. The sticking points in this conception are the lack of enough professionals in residential settings, the irrelevance of many of their assessment techniques to the human and behavioral problems of the retarded, and an incredible myriad of interdisciplinary differences and mutual misunderstandings about how to implement a multi-faceted treatment plan once it is formulated. This model may never have been given a fair test, and perhaps it should. But in addition, radically new and less expensive approaches must be tried. This prevailing model is probably no more feasible for solving the problems of all the developmentally disabled than psychoanalytic therapy is for solving the problems of all the mentally ill. Group approaches involving nonprofessional personnel must be perfected, and how to do that must be the subject of intensive investigation. The courts have served fair warning that we must act in this direction soon.

ALTERNATIVES TO RESIDENTIAL CARE

Many states have recently begun to try a new solution to the problems of residential programs for the developmentally disabled. That solution is to replace residential care with community-based care. The central strategy is to remove the developmentally disabled from institutions and to place them in halfway houses, foster homes, condominiums, or even their own homes while providing them with economic assistance in the form of welfare payments, workshop placements, and jobs and social assistance in the form of legal aid, medical advocates and organized companionship and recreational opportunities. Other states have developed combination residential and day care centers that are located in urban settings and which draw on community resources rather than on inhouse services. These are healthy developments, and close observers of them hold great hope for their success. So do I, but I do not expect established residential facilities to wilt away as these new alternatives blossom, nor do I expect the new alternatives to flourish without a major new effort to research and remove the obstacles that confront them. There are problems of zoning regulations, transportation to dispersed services, coordinating administratively separate agencies, spelling out for parents the advantages of community over residential treatment, and so on and on.

I believe that these innovative alternatives are our brightest prospects for change. As in any area of human endeavor, it is easier to recruit the enthusiasm of talented people for the building of a new institution than it is for the changing of an old. Undoing the errors of past innovators requires energy that might be used to help more directly, and it seems negative and unrewarding. But when the old institutions preside over the noncare of disadvantaged people, can we justify putting all of our energy into new systems? I think not, largely because I believe that the success of these new efforts stems from the commitment and effort of their developers to meeting the needs of their clients. These pioneers have not found one clearly superior alternative to one clearly evil old system. If they are successful, it will be because they are experimenting with many alternatives, and they are tailoring these alternatives to the particular needs of the people they serve using the resources that are available to them. That same strategy could and should be applied within existing residential facilities for the developmentally disabled. Those facilities are not bankrupt. They are peopled with able and humane people who have great economic resources at their command and who can command the ideas and labor of talented outsiders.

I have reviewed four ways that have been tried to improve residential services for the retarded, and I have stressed the shortcomings of each. But these ways are still useful:

1. We need additional and more refined knowledge, and research can provide it. But that research needs to be refocused on the problems of changing institutions without undoing their good features. To achieve that, research will require a new partnership in action between scientists and employees of residential facilities. Too often, scientists have treated residents of institutions as captive colonies of research subjects whom they have exploited for the purpose of answering questions that have no bearing on the human condition of those residents. Too often, administrators and employees of residential facilities have aided and abetted this sterile approach. Both sides of this potential partnership should seek the help of the other, and offer their cooperation in return. It is time to recognize that residential facilities are not laboratories for socially uncommitted scientists. It is time to recognize that the responsibility for changing institutions lies with their current employees, and that one resource which they can tap to help them change is the talent of the scientists who lurk in secluded laboratories on their very grounds. I have at various times in the past enlisted the cooperation of perhaps a dozen different residential facilities for research projects I wished to perform. Only once in the course of negotiating their cooperation did an administrator ask what I would do in return for his help and that of his staff. I hope that in the future I will find more administrators seeking a quid pro quo, and that the request will be for something that will benefit the residents of the facility in which I seek to work.

2. Management and inservice training must be made more effective. It should probably focus on ways of changing existing patterns of care and treatment. It might start from the premise that those who work daily with the

developmentally disabled know about them in the ways that are important to know, and reject the didactic approach of instructing them in the jargon which the various professions use to convey their understanding of the disabled. It might focus on both the needs of residents and ways to surmount obstacles which the institutional system puts in the path of meeting those needs.

3. All residential facilities should seek to be accredited, and they should participate actively in evaluating and improving the procedures used to decide on accreditation. Particular emphasis needs to be placed on how to evaluate the process of delivery upon the outcomes of residential services.

4. More court actions should be initiated. These should include individual liability court actions as well as class actions. But we should recognize that the main values of such actions are to stimulate reform and formalize broad principles to guide that reform.

It was probably inevitable that the most exciting prospects for improving treatment of the retarded would center in residential facilities, because those facilities have been our most extensively developed treatment modalities for the retarded. In the eyes of many, residential facilities and their personnel have also been one of the most reactionary forces in the battle to improve the treatment of the retarded. The opportunity is here to change this. All that is required is for these facilities to lead the way in innovating new services, whether they be institutional or community based. Inadequate care can be provided anywhere. Institutions do not have a corner on its market. They should be allowed to help the newly emerging community-based programs reach and maintain excellence.

Role of University Affiliated Facilities In the Developmental Disabilities Act

Julius S. Cohen

INTRODUCTION

The Developmental Disabilities Services and Facilities Construction Act of 1970, P.L. 91-517 contains two major sections. Title I addresses itself to the problems of direct service to the developmentally disabled. It creates a mechanism for planning, establishing priorities and meeting the needs of this group. Title II, the University Affiliated Facilities portion of the law, extends the concept of interdisciplinary training to meet the complex manpower needs of the field. Although presented in separate titles, the two components–service needs of the developmentally disabled and the manpower required–are inexorably intertwined. This paper will explore that relationship and the extent to which the University Affiliated Facilities (UAF's) can serve as a resource and as a base of technical assistance to the Developmental Disabilities Councils and service agencies in their states or regions.

BACKGROUND

In 1962, the President's Panel on Mental Retardation issued its report on the needs of the mentally retarded. One section of that report recommended that skilled manpower must be developed so that adequate services could be provided for the millions of mentally retarded individuals in American society. As one result of this report, Congress passed P.L. 88-164, Mental Retardation Facilities Construction Act of 1963. Part A of that legislation provided for the development and construction of mental retardation research centers. Part C provided for the development of a wide variety of needed community facilities. Part B of P.L. 88-164 created the University Affiliated Facilities Program. The initial concept of the University Affiliated Facilities, as embodied in Part B, provided for the construction of facilities to house those exemplary and innovative interdisciplinary training programs that were designed to meet the complex manpower needs in this field. Initially, there was a strong emphasis on medicine and closely related disciplines.

The primary mission of the University Affiliated Facilities is to serve the developmentally disabled of all ages by providing: (1) interdisciplinary training of administrative, professional, technical, direct care and other personnel who provide the spectrum of services required by the target population; (2) research training for carrying out appropriate research; (3) assistance in the process of establishing state and regional objectives and evaluating the effectiveness with which these are being met; and (4) technical assistance to community agency personnel.

By 1965, it became clear that the construction authority was insufficient to fill the legislative intent and that program support money was needed to provide both staff and trainees in these facilities. Accordingly, in the 1965 amendments to the Social Security Act, the Children's Bureau (now the Maternal and Child Health Services of the Health Service and Mental Health Administration) was authorized to support training programs in University Affiliated Facilities under Section 511 of the Act. The major intent here was to provide support for training of physicians and other health related personnel. These funds form one base of support for UAF program activities.

Twenty such facilities were constructed with funds from P.L. 88-164. In addition to the constructed facilities, there are approximately nine other operational programs, some with facilities of their own which were not constructed with these funds.

In the Spring of 1968, a group of directors and administrators of the developing University Affiliated Facilities met during the AAMD convention in Denver. Out of this informal gathering grew the Association of University Affiliated Facilities.

The group organized: (1) to share information about common problems and strengths; (2) to provide a more unified approach to funding agencies; (3) to assist in the process of information, personnel, student and data exchange; and (4) ultimately to have an impact on the development of new legislation in the field.

While the UAF's originally had started their development in direct relationship to mental retardation programs, they, in fact, adopted the principle of the developmental disabilities concept as a training reality prior to the language change in P.L. 91-517.

The Association defines a University Affiliated Facility as a university-based or university-affiliated interdisciplinary program for the development of skilled manpower in the field of mental retardation and other developmental disabilities which meets the following criteria. The facility:

(1) Leads in the demonstration of improved means for provision of exemplary services for the developmentally disabled.

(2) Meets the criterion of an administrative identification within a university which demonstrates significant long-term commitment to the concept of interdisciplinary training in mental retardation and other developmental disabilities.

(3) Provides training programs which are of an interdisciplinary nature and encompass a broad and comprehensive range of disciplines.

(4) Provides a program designed to be relevant to the manpower needs of the area or regions served by the university.

(5) Is intrinsically related to exemplary service functions in such a way that such functions provide practica of academic excellence for the students.

(6) Insures that the UAF is responsible for interdisciplinary programs which demonstrate a capacity to utilize the resources of the university and the region:

(a) to develop new approaches in utilization of the disciplines of mental retardation and other developmental disabilities, and

(b) to identify new roles for new disciplines.

Currently, over 35 University Affiliated Facilities which have received funding from the Division of Developmental Disabilities in the Rehabilitation Services Administration, the Maternal and Child Health Service and the Bureau for the Education of the Handicapped are either in constructed buildings or are functioning prior to such construction. As these facilities proceed in developing their complex and innovative programs, it becomes increasingly apparent that there is a greater need to share experiences, ideas, and objectives in order to enhance the operation of each facility and the services that the facility can provide to its states and regions. The UAF's themselves are in a unique position to offer certain services to federal and state governmental agencies concerned with program planning and development, program operation and evaluation and direct service.

Because of the delays incurred in construction and securing staff, and in recruiting students, the University Affiliated Facilities are just beginning to make their presence felt in the field. The funds allocated to Title II of P.L. 91-517 are not drawn from Title I, but in fact, may be the mechanism to insure that the efforts intended under Title I are achieved because of the manpower trained by the USAF's. These programs are just beginning to demonstrate their value to the field. Nevertheless, there is the need and interest in the University Affiliated Facilities providing (a) the data base which will offer a measure of the contribution of these individual programs to the nation; (b) data on the nature and variety of existing services and on new, relevant services for the developmentally disabled and their families; (c) information on the quality and impact of interdisciplinary training; and (d) an exchange of information, experiences, and ideas to aid and improve all aspects of the administration of training and exemplary service programs.

The Association of University Affiliated Facilities has, as a goal, more effective communication and cooperation between the independent units. To achieve this, annual meetings of the directors and administrators have been held. Furthermore, for the past five years, one of the regions has operated a consortium of programs within the region including seven University Affiliated Facilities, one training program funded only by state rather than federal government, and two training programs in Canada. This regional concept and the close cooperation of regional office staff help insure a close coordination between the UAF's and the needs of the various states in that region.

In 1970, Congress passed P.L. 91-517. Title I of that law amended Part C of P.L. 88-164 and mandated, among other things, the establishment of State Developmental Disability Councils. Title II extended Part B of P.L. 88-164 and authorized core support for University Affiliated Facilities. A formula grant program was established to provide support for states in planning, administration, services, and construction of facilities for the developmentally disabled. The formula grant program operates through two main mechanisms: The first, the State Planning and Advisory Council and the second, designated state agencies. The Council is responsible for establishing priorities for the direction, development, and growth of programs. In order to receive the federal allocation, the state must have a state plan that was approved by the Secretary of the Department of Health, Education, and Welfare. The Advisory Council is responsible for reviewing and evaluating the state plan and submitting appropriate revisions. The state plan must consider all program areas including, but not limited to: vocational rehabilitation, public assistance, social services, crippled children services, education of the handicapped, medical assistance, maternal and child health, comprehensive health planning, and mental health.

The new program of federal support for interdisciplinary training programs at University Affiliated Facilities under Title II was seen as a way of tying together provision for the on-going manpower need with the proposed expansion of services (under Title I) to developmentally disabled throughout each state. A great potential exists for the UAF's to interact with state and regional planning agencies for the improvement of the quality and quantity of services available to the developmentally disabled and their families. There needs to be a common awareness of methods by which the UAF's can provide technical assistance to planning and administrative personnel of state agencies. Approaches to meet the state manpower needs should be reflected, in part, through the UAF's. The University Affiliated Facilities also can help to generate model programs which could be used both in the high density disability areas as well as the less densely populated regions of the state.

THE CURRENT ROLE OF THE UNIVERSITY AFFILIATED FACILITIES

It should be helpful to explore the role of University Affiliated Facilities and determine what their potential actually is, and the extent to which they are providing service to the field. In the preparation of this paper, a request was sent to University Affiliated Facilities to obtain information on how each related to the Developmental Disability Council and to the service agencies in the state or region served by the facility. This paper will not identify a particular activity with a specific facility, but rather will use the information collected to highlight some of the ways in which UAF's relate to their geographic areas.

Training

The University Affiliated Facility represents a unique concept and an outstanding resource for the states and regions in which it exists. While there is much variation in organization and structure among the UAF's, there are some common factors which enhance their value to the field. The first, and perhaps most important characteristic, is that the University Affiliated Facilities draw together a number of highly skilled individuals from a wide variety of disciplines who have common interests in the field of mental retardation and developmental disabilities. This collection of individuals with concerns in a single area may be seen as a critical mass, the existence of which stimulates activities in the area and also attracts additional resources, students, and community practitioners, and the attention of the general citizenry to the field, its needs, and accomplishments.

Rather than merely providing additional training, the interdisciplinary mix of staff and students serves as a basis for improved community service to the field. That is, students are trained in conjunction with other students from other disciplines. They are able to see and understand how other disciplines function and the most effective way for them to use each other. In addition, the general University Affiliated Facility pattern is to maintain a very strong outreach effort, seeking to provide in-service, continuing, and adult education to the wide variety of practitioners, volunteers, family, and interested community persons. This effort is significant both in upgrading the skills of personnel in the field and also in providing them with models of service which they can adapt to their own practice.

In response to the requirement in P.L. 91-517 that the University Affiliated Facilities relate to community college programs, most of the programs have developed mechanisms to work with this group of individuals who are starting careers as support personnel in community programs. A significant portion of this thrust is in efforts with para-professional workers in residential facilities, dental hygienists, as well as other personnel involved in a wide variety of community-based programs. The formalization of the relationships with the community colleges has enabled community college students to obtain part of their training at UAF's and, probably even more important, has provided professionals in training the opportunity to work directly with support personnel as part of their training experience.

Technical Assistance

With the large number of individuals representing a wide variety of disciplines available within their programs, the University Affiliated Facilities have served state and local agencies and State Developmental Disability Councils by providing technical assistance and advice. Expertise in these UAF programs ranges through a wide variety of disciplines and, since the programs are essentially training rather than service agencies, they have been able to participate in the process with minimum role conflicts. University Affiliated Facilities staff members have assisted states in the development of the State Developmental Disabilities Plans and, in many of the states, there is a representative of the UAF on the state council.

This can prove to be a most important Council appointment as the University Affiliated Facility can represent one of the most significant resources to the planning, evaluation and monitoring efforts of the Council. In addition, in many of the states and in several of the regions, staff of the UAF's have provided training programs for the members of the Developmental Disabilities Council to enable them to function more adequately in their assigned roles. Because of the need to coordinate the University Affiliated Facilities' activities with those operated under Title I, because of the potential value of the input of the University Affiliated Facilities to the entire Council process, and because of the flexibility and variety of services provided through University Affiliated Facilities programs, I believe that each Council should have, as members, a representative from each of the University Affiliated Facilities that serve its state.

Outreach

Unlike many University programs, the concept of the University Affiliated Facility has included a very strong community outreach component. This outreach has been marked by a number of significant efforts. First, rather than merely providing preservice training for professionals, inservice and community education has become an important part of most UAF activities. Moreover, models of service have been established which permit a great involvement of community agencies and personnel within University Affiliated Facilities. For example, in several of the UAF's which are serving rural, sparcely populated parts of states, a number of approaches have been designed to assist practitioners from these areas in obtaining the more complete services of the developmental disabilities team. There has been extensive use of video tape, traveling teams, and telephone consultation to demonstrate what can be done in these areas and to provide a back-up support for the local practitioner.

Concerned with the national goal of returning as many residents as possible from institutions to the community, the UAF's have focused on two areas of activity. First, there has been a major effort to address themselves to the needs of institutional personnel and to upgrade institutional programs and services so as to enhance the likelihood of residents being returned to the community. At the same time, concerned with the lack of community support agencies, the UAF's have worked to demonstrate what kinds of services are needed in the community and ways in which personnel from a wide variety of community agencies could be trained most effectively and efficiently to meet the needs of individuals who are returned to the community. As another aspect of this effort, there has been an emphasis on the prevention of institutionalization with programs designed to assist parents and community agencies to maintain developmentally disabled individuals in the home community.

The outreach concept was extended (and reversed) to include planning for the development of the University Affiliated Facility. In many of the university settings, the original planning committee consisted of individuals representing the university, various state agencies, local agencies involved in delivery of services to the developmentally disabled, and consumer representatives. This type of input has, in many instances, been maintained through the establishment of a facility state advisory committee. These advisory committees include representatives of the various state departments who are responsible for serving the developmentally disabled as well as consumer groups. Thus, the relevance of the activities of the facility in providing training for present and future professional staff is monitored by the continued input of the service agency personnel and consumers.

Service and Consultation

While the major concern of the University Affiliated Facilities is in the training of personnel for the field, a considerable portion of their activity is designed to provide service and consultation to service agencies. Generally, the UAF service component is relatively small and is designed to meet training needs and to provide models of clinical service activities which could be replicated in the field, not to provide a major service to the state and region. Nevertheless, a significant number of individuals and their families are served by the programs. Because of the depth and variety of staff, the UAF's frequently are called upon to provide consultation and/or service for specific cases and to assist in developing management plans for difficult to diagnose individuals. In this regard they work both with state residential facilities as well as with a wide variety of community programs.

There is some emphasis on work with individuals with multiple handicaps who present particularly challenging problems for service agencies. For example, a few of the UAF's are working with Deaf-Blind-Retarded persons; others with severely and profoundly retarded who also have severe physical limitations.

The University Affiliated Facilities provide consultation and referral services for regional mental retardation clinics, and in some settings they operate a field team which maintains liaison with community programs, provides consultation in the field, and makes provision for continuing education of the staff of local agencies. This inservice training component is an important adjunct to the clinical service activity and demonstrates an optimal use of cases to improve practice.

Without a control on the number of individuals served directly, it would not be possible for the University Affiliated Facilities to perform their vital training function. If the contributions of the program are viewed only in relationship to the number of individuals and families directly served, the cost per case would appear to be extremely high. However, when the University Affiliated Facilities are viewed in the light of their true purpose, that is training and using the cases served to upgrade community programs, then a better balance would be seen. For example, it is not unusual for a single case to be seen by a number of students from a dozen different disciplines. The experience of the students would vary and their contact might be directly with the family or they might observe the process via observation rooms or monitor it by television. The same case also could be used as a basis for inservice training of agency practitioners, and to assist them in improving their services, not only to the individual being directly served but to many others similarly constituted.

A video tape of the case could be used for training other students, practitioners and for community education activities. Thus, a single case is used many times over to meet the needs of the individual and the family, to affect the service system, and to provide for the training needs of a large number of preservice and inservice individuals. To cite one example, a severely retarded cerebral palsied youngster of 18 months was referred by a community mental retardation service agency for evaluation by a University Affiliated Facility in the university setting. The entire staffing process was video taped and the tapes used in student training. In addition, the tapes were brought back to the home community, which was a sparsely settled section of the state. A meeting was scheduled to show what the University Affiliated Facility team had done, their staffing conference and the recommendations they made for the child. In addition, the meeting was seen as a vehicle for inservice training and for stimulating cooperation and coordination among the local child-service agencies. Individuals representing most of the health, education, and social service agencies in the area participated. During the conference it was found that four different physical therapy treatment programs had been designed by four different agencies in the community, each without the knowledge of the other. It should be noted that in some regards, these treatment plans were in conflict with each other. It was found that the family had been utilizing a tremendous portion of the very limited resources of the community and that agency efforts were not coordinated at all. The case provided a basis for examining the problems of coordination in a rural community with limited resources and the need to coordinate and cooperate among service activities. During subsequent months, there have been significant changes made in the professional practice in these rural counties.

How is the impact of this case evaluated? From one point of view the University Affiliated Facilities served only a single individual. However, it is the multiplier effect of the University Affiliated Facilities activities which makes it such a significant aspect of the total community program. The role in preventing the duplication of services, as exemplified in the situation cited, is an important one, as is the extended use of the case for training.

Service to Developmental Disabilities Councils

The University Affiliated Facilities have a great potential in direct service to the Councils in their states or regions. They can assist in establishing priorities; developing, modifying, and monitoring state plans; and in providing training experiences and various additional services designed specifically to meet the priorities and needs set forth in the state plan. Already, this is being done in a number of states and regions. However, this type of interrelationship between the UAF's and the Developmental Disability Council should be an integral program activity of both agencies. The University Affiliated Facilities are uniquely situated to assist in efforts in disseminating information to the field, collecting and organizing data, and supporting service functions. They can initiate the sharing of ideas and the exchange of models of practice and service.

Because of the existence of the Association of University Affiliated Facilities, activities which prove to be successful in one region of the country are being transferred quickly to other regions where they can be applied. University Affiliated Facilities have provided direct consultation to state developmental disabilities councils and have, furthermore, staff from the facilities serving on the councils. In some states, the University Affiliated Facilities provide essential information and library service for the Council and other interested persons. While these kinds of relationships now exist, they must be developed much more fully, and new ones must be explored and created.

Each state plan addresses itself to needed services in terms of priorities established by the Developmental Disability Council. The University Affiliated Facility has the capabilities for developing and administering training and selected service delivery programs for these priority needs. For example, in one state, the need for regional fixed points of referral was determined to be the number one priority item. The University Affiliated Facility developed a model plan of fixed referral that had been submitted for state support. In other situations, because of the variety of audiences to which the UAF's address themselves, the training of parents has become an important aspect of the total effort. A variety of programs have been developed in this area and have done much to assist in maintaining families at their optimum level.

Research

The research capabilities of the University Affiliated Facilities is an important adjunct to their total value. Through their research activities, both basic and applied, new approaches to the problems of the developmentally disabled can be developed and evaluated. The programs range from basic research into genetic or other biological factors to the development and evaluation of curriculum for educating handicapped developmentally disabled individuals as well as practitioners in the field.

SUMMARY

The interdisciplinary training concept reflected in the development of the University Affiliated Facilities has been in existence for almost a decade. During that time, major efforts have been extended in conceptualizing programs, constructing facilities, and in organizing a substantial funding base for the programs. Throughout the early years of the program, there were relatively few trainees and the impact of programs was not very significant.

However, during the past several years, there has been an increasingly strong thrust by the University Affiliated Facilities. Their outreach activities and their efforts to assist state developmental disability councils in identifying and meeting the needs of states and regions have represented one of the most significant advances in the field. The training of preservice students at all levels, inservice training to upgrade and modify patterns of practice and service, and the development and utilization of a wide variety of teaching approaches has begun to have an effect in many of the regions throughout the country.

While the immediate number of families and individuals served by the programs is not large, the spin-off effects of University Affiliated Facilities programs are great. A single case may serve as a model which will improve services to many families. Preservice and inservice training have a long range ripple effect which may take years to fully assess. The University Affiliated Facilities are willing and able to become full partners in the implementation of the Developmental Disabilities Act. It will be primarily by close coordination of the needs addressed under Title I, and the manpower which can be provided by the UAF's under Title II, that the greatest progress will be shown. University Affiliated Facilities representation on Developmental Disability Councils will help to insure closely coordinated efforts. The University Affiliated Facilities is a singular resource in many states and regions which must be utilized as fully as possible.

INPUT FROM THE CONFERENCE

This paper was presented at two sessions during the National Conference for State Planning and Advisory Councils on Services and Facilities for the Developmentally Disabled. The audience at each session was split equally between individuals from state councils, and staff from University Affiliated Facilities. Rather than read the paper, the author presented a 10 to 15-minute summary. The following three points were covered: (1) common aspects of most of the facilities programs; (2) problem areas; and (3) future trends and directions.

The common aspects included a prime factor: the facility being a university related training program. In all instances the programs are interdisciplinary in nature drawing together students from many disciplines. The extent of community outreach of the programs was noted as was the extent to which they can serve as new models of service delivery.

The primary problem area cited was that of evaluating the effectiveness of the University Affiliated Programs. The community is interested in the number of persons actually served, usually a relatively small number within facility programs. The University usually is interested in research and publications, areas not stressed within the programs. While there is a general agreement that there are considerable manpower needs, the University Affiliated Facility programs are just beginning to demonstrate their ability to train significant numbers of persons. Because of the extended delays between initial legislation and the current stage of development, the programs are having some difficulty as their efforts are being evaluated.

Another problem area that was presented is the lack of a clear, mandated relationship between the University Affiliated Facilities and the state plan. While there was close cooperation with the facility in the development of the plan in some states, in others state planners were without knowledge of the existence of the program or its mandate to help serve the manpower needs of the state. There was also some feeling that the Title II monies would be added to Title I if the University Affiliated Facilities program did not exist. Our presentation emphasized that this was not so, and moreover, the facilities did not have any funds to do what the state councils might want of them. Most activities undertaken to assist the council and implement the state plan would require additional sources of funds for use by the facilities.

The future directions of the programs were pointed out as capitalizing on the strengths of the University Affiliated Facilities programs for providing training, technical assistance, advice and service consultation. The importance of the outreach activities was stated as well as the programs' ability to show other models of service delivery.

Following the brief presentation by the author, there was (in each session) an intense discussion in which almost everyone participated. The discussion highlighted several factors which both University Affiliated Facility staff and state council members must keep in mind:

(1) There is much confusion among some people concerning the role of the University Affiliated Facilities.

(2) Many council members did not know of the program and did not have a facility within their state.

(3) A method must be evolved to insure that each state council has access to a University Affiliated Facility program.

(4) Having learned of the resources, several members of the audience indicated that they would work toward the development of a relationship between the programs in their home states.

(5) The funding sources currently available to the University Affiliated Facilities do not insure that State Council needs will be met.

(6) Some questions were raised concerning the viability of an interdisciplinary approach to manpower development which can only be answered as time permits research regarding on-the-job functioning of individuals trained in this manner.

(7) The University Affiliated Facilities require additional resources for the development of long term manpower, and an ongoing relationship with the State Council should be a requirement.

(8) As does the National Advisory Council, each state should have a University Affiliated Facility subcommittee to insure the full utilization of the program.

(9) In an effort to provide a broader understanding of each other's activities, the State Councils should schedule a meeting at the University Affiliated Facility with which they are or should be working.

Maximum Utilization Of Transportation Systems

William J. Bean

INTRODUCTION

The "developmentally disabled" obviously do not present a single constellation of limitations, mental or physical. However, in order to develop a perspective on the topic of transportation, we may conveniently address the question by assuming that the limitations may range on a continuum from severe mental retardation with no physical limitation to gross physical limitation with no mental retardation. In the one simplified case, many of the transportation problems can be overcome by training of the individual so that he can perform regardless of any mental deficit; on the other hand, gross physical limitations may require special vehicle modification and personal assistance.

In practice, of course, the problems are not all that dichotomous. Further, the age of the individual under consideration affects the nature of the problem, so that very young children of any physical or mental condition are not generally held to be fully capable of independent travel.

TRANSPORTATION AND THE PHYSICALLY DISABLED

The problems facing the physically disabled in regard to transportation in this paper generally have been identified as to the types of transportation available: use of the automobile, and use of mass transportation.

Judge Sherman Finesilver of the University of Denver Law School has been among the persons who have been studying the problems facing the handicapped driver; that interest beginning first with an interest in the deaf driver, then extending inquiry into the more severely physically (orthopedically) disabled person.

The most basic physical requirement for driving seems to be vision; compensation for most other conditions can generally be achieved through specialized equipment or specialized training. Examples are extra mirrors to help the deaf person be more aware of on-coming and cross street traffic, or hand controls for persons who have lost the use of their lower extremities.

A symposium held in Denver in 1969, under the leadership of Judge Finesilver, focused on licensing, retraining (following onset of disability), accident records, driver weaknesses and shortcomings, and insurance considerations. Among the findings of the experts and the studies reported at the Denver symposium were:

- Physically disabled drivers are among the most safety conscious and have safety records as good or better than other drivers.
- Insurance companies report positive attitudes toward disabled drivers and no discriminatory treatment, although the disabled themselves report instances of difficulty in obtaining insurance at standard rates.
- There is marked need for driver training focused on the needs of the disabled.
- There is a need for uniform testing and evaluation of special equipment (hand controls, etc.) needed by disabled drivers.
- Special parking privileges are a must if the disabled driver is to make full use of the independence the automobile can give him.
- The disabled driver needs some means of summoning assistance in the event of an automobile breakdown.

Increasingly, attention is being given by those concerned with rehabilitation to the important contribution an automobile can make to the full independence of a severely disabled person. Several comprehensive rehabilitation centers, as a matter of routine, evaluate persons for driver training, and may even offer such training as part of the overall program. Also, several states include in high school driving training courses special training for disabled drivers. A study done in the Los Angeles schools indicates that: (1) knowledge of safe driving requirements and attitude are the prime requisite for success as they are with all drivers; (2) the rate of success among the disabled student group (95 or 182 or 82.1 percent) more than justifies the added expense and effort to provide driver training to this group; and (3) the rate of success, as determined by being able to qualify for licensing, was highest in those qualifying as "orthopedic," but a significant number of persons with cerebral palsy were also successful.

A very significant study on the needs of the physically disabled in the use of public transportation was conducted for the Department of Transportation by Abt Associates of Cambridge, Massachusetts. The report produced by this study, "Travel Barriers," examined all modes of transportation available in travel from Boston to Washington, with a focus on the elements of each mode of transit that posed problems to those with mobility limitations. An innovative approach used in the Abt study was the filming of a motion picture of each mode, so that a person who may not have experienced, say, the problems of emplaning on an airliner could have the vicarious experience of seeing a flight of steps required for boarding.

The Abt study identified the following problems faced by the disabled in use of public transportation, any one of which could prevent the use of a particular mode. As the number of these hurdles accumulates, the possibility of success becomes more and more problematic:

- Sudden movement
- ability to ride standing
- ability for rapid self locomotion
- ability to move in crowds
- ability to wait standing
- ability to change levels (i.e., steps)
- escalators
- narrow aisles
- long walking distances
- baggage

In addition to the problems directly connected with the mechanics of transportation are such related problems as lack of well defined signs for those who are visually handicapped, or the lack of accessible restrooms.

Overcoming the problems inherent in present mass transit clearly calls for redesign of equipment and systems. Problems still remain, especially movement from the transit stops to the passenger's ultimate destination. Of course, these problems exist for all users/systems, as seen in the term "kiss and ride" used by transit designers to describe the person who is dropped off at the transit station and later picked up by their spouse. However, for the physically disabled, even short distances of a block or two may be enough to use of an accessible system unless there are such design features as curb cuts, close parking, etc.

TRANSPORTATION AND THE MENTALLY RETARDED

A recent publication of the President's Committee on the Mentally Retarded entitled *Transportation and the Mentally Retarded* provides the most thorough examination of this topic that is currently available. Though offered as the anonymous work of the contractor, it is chiefly the work of Ms. Linda Sadler, who was with Harold F. Wise Associates at the time of writing.[1] Although the focus of *Transportation and the Mentally Retarded* is more narrow than the developmentally disabled in total, many of the concepts discussed therein have relevance, especially when addressing the problems of dependency that may accrue to the individual who is dependent from birth.

Independent vs. Dependent Travel

Transportation and the Mentally Retarded makes a distinction between independent travel performed by the person, and travel in which the individual is highly dependent on others, or on a specially designed system. Drawing heavily on the results obtained by Arnold Cortazzo and Robert Sansone at the Sunland Training Center in Florida, it is pointed out that most mentally retarded people have the potential for developing independent travel capabilities; that is, travel using modes regularly used by "normal" people: walking, public buses, bicycles, trains, even the automobile.

Transportation and the Mentally Retarded makes the case for developing independent travel in the individual through several approaches interrelated to the different modes of transportation. First of all, the potential for success in training the bulk of the mentally retarded is cited. Cortazzo and Sansone report that in work with trainable retarded adolescents and young adults aged 17 to 40, and with measured I.Q.'s from 17 to 40, 199 of 378 trainees learned to travel independently. I.Q. was not seen as a particularly important criteria for determining independent success. The important characteristics were social maturity, emotional stability, and parental cooperation. It is reported that individuals labeled as border-line or mildly retarded can be successfully trained to travel independently. Even for those more retarded, success can generally be obtained.

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[1] Ms. Sadler has reviewed the portion of this paper dealing with her earlier publication.

The desire to be as independent as possible motivates the mentally retarded as strongly as others, and this drive is cited as one of the positive elements in support of training mentally retarded in independent travel skills.

Another reason to encourage independent travel whenever possible is the burden on parents. Keeping mentally retarded youth and adults transportation-dependent defeats the provision of other services to encourage independence. One of the major problems facing any program is the expectation that independent travel is impossible for the mentally retarded. Many programs, reportedly, have never given consideration to this possibility and are surprised at the results obtained by Cortazzo and Sansone.

The major barrier to independent travel is the lack of suitable public transportation, especially in rural areas. In many areas of the country, there is simply no public transportation. (The extent to which suitable public transportation is available for specific facilities is another question. This should be considered in planning when facilities are located. Most Americans are dependent, psychologically as well as physically, on the automobile. People who are mentally retarded are, again, no exception. *Transportation and the Mentally Retarded* cites at least two programs which have been successful in teaching mentally retarded people to be successful drivers. One concern cited is that the retarded driver may lack a capacity for making correct decisions when an emergency arises. This has been countered by providing visually oriented training and more behind the wheel training.

In addition to buses and the self-driven automobile, other modes of transportation are available to and used by the mentally retarded, and all of these modes may require some special attention and training in their use.

Walking is likely to be the most frequently used mode of transportation, though seldom thought of in this manner. Special "survival" skills should be taught. Systematic investigation has begun in the area of special needs of mentally retarded youths and adults in walking (traffic lights, judging speed and distance of on-coming vehicles, etc.), though much remains to be done.

In addition to infrequent bus service, the mentally retarded person may become confused over changes in schedules, transferring, determining which bus to take, where to get off, and the like. Those skills can be taught by agencies and parents. In addition, bus drivers can help, if they recognize the need, which suggests that training in these matters should be part of the regular training for bus drivers.

Recommendations of the report in regard to independent travel are: (1) provide sufficient staff and time for independent travel training in all agency and school programs serving the mentally retarded; (2) provide special driver education to mentally retarded individuals who are capable and desirous of driving; (3)

train public transportation personnel to recognize mentally retarded individuals (teach mentally retarded persons to seek help from transit personnel whenever in doubt); and (4) require that all handicapped children be educated, especially in "social survival skills" such as transportation.

Improvement of Dependent Travel

The second major focus of *Transportation and the Mentally Retarded* relates to systems for dependent travel, that is, travel services in *addition* to or in *lieu* of the travel modes used by "normal" individuals. Considerations cited apply equally to special supplementary systems for the physically disabled.

Several concerns emerge whenever a special program for transportation is launched, among which are funding, staff and volunteer resources, safety, insurance, and scheduling, as well as whether to tie up capital in purchase of equipment or to lease. Further decisions must be made as to mode of transportation: automobiles, vans, taxis, buses.

There are perhaps as many ways of paying for transportation services as there are programs. Among those reported by *Transportation and the Mentally Retarded* are state per diem/student payment, state operated small buses, contracted carriers, and full or partial assumption of costs by parents. The very diversity of payment sources makes it difficult to make an estimate of the actual costs incurred. One agency reports that 30% of its budget goes for transportation. Other programs limit costs to giving out bus tokens. California will allow public funds for transportation for trainable or moderately retarded individuals, but not for the educable retarded, feeling that educable persons do not have transportation needs different from other students. The following chart indicates costs by various modes of transportation:

	Per Person Per Day
• By car–$.10 a mile	$1.00
• By bus–$.40 per trip	.80
• By contracted public transit	1.60
• By small school buses	2.54
• By vans–door to door	3.00
• By private car	2.80

Staff and volunteers are sometimes used by agencies to transport clients those agencies. Sometimes aides accompany a driver to assist in emergencies and help maintain discipline. Volunteer groups such as civic clubs and fire departments have been enlisted to provide transportation services and/or equipment. Car pools organized by parents are frequently formed.

Insurance looms as a problem. State laws differ, as does the willingness of different firms to insure volunteer or agency programs. *Transportation and the Mentally Retarded* quotes a New York firm as determining from experience that insurance coverage is most needed in "third party" situations–public liability, auto liability, and malpractice. Workmen's compensation, which covers employees, should be extended to volunteer workers.

Automobiles, vans, taxis, and buses are all used in one or another of the programs. Parents and volunteers frequently use cars, while small agencies may use vans. Sometimes taxis are used on a contract basis. Buses, while offering some economy may require lengthy trips.

Among the recommendations made in *Transportation and the Mentally Retarded* are: (1) use of transportation time to continue instruction through taped lessons and the like; (2) development of specialized systems such as dial-a-bus or taxi-bus combinations; (3) combining of transportation services for the retarded with other specialized transportation systems; (4) provision of better training of transportation personnel; (5) seeking legislation, especially for operating subsidies for specialized systems; (6) centralizing all services programs so suplicative systems with different destinations are not needed; and (7) integration of transportation into other activities.

(One participant at the National Conference of the National Advisory Council told of a simple adjustment made in buses used to transport children: the seats were raised and turned to face the windows, thus giving the children an opportunity to observe city life as they went to and from their respective destination. Boredom [and resultant misbehavior] decreased, and the long trip was transformed into a stimulating experience.)

COMMENTS

In providing transportation for specialized services, transportation needs are somewhat simplified. The service center in each case is something like the hub of a wheel, with spokes radiating to points away from the hub. However, a major adult activity for many developmentally disabled will be work. To the extent that the individual can enter into the competitive labor market, the hub-perimeter analogy does not hold. In this case, travel is more likely to be from one point to another somewhere within the wheel with few traveling the same route. Even within well defined job markets such as the Washington, D.C. metropolitan area, data shows that 40 percent of those living in the suburbs now also work in the suburbs, and this ratio is expected to increase.

Time is another factor delineating transportation needs for agency services from those needed for non-agency life activities. Many service agencies begin operations later in the morning than most employers, and end earlier in the day. Some transportation activities, which are adequate for service programs, such as use of volunteers and extended bus routes, will not meet the time requirements of employment. It is one thing to find a volunteer able to get a child to a service program at 9:30 a.m., and quite another to get an adult to work at 7:30 a.m. Attendance presents similar problems. Neither a service program or the individual client is damaged much by an occasional absence when transportation fails. An employer, on the other hand, requires a much better record.

The solution to many of these problems lies in the development of independent travel for the individuals involved. *Transportation and the Mentally Retarded* suggests that transportation problems could be solved if the family would move near a bus stop. That is not, perhaps, such a bad suggestion. The Post Office reports that one in three addresses are changed each year. Very few people live in the same house while their children are growing up. In light of this mobility, families of a developmentally disabled child might be advised to consider the availability of transportation whenever they make a move. If the child is only five at the time, this may seem irrelevant. However, if he is able to begin to use public transportation from time to time as he grows up, there will not be a transportation crisis when he is age 16 or so, when it would seem to be asking too much to move merely to solve the transportation problems of one family member.

Service agencies, also, should keep the availability of public transportation in mind when locating programs. Even if these programs serve children of parents who can drive them in for services, the availability of nearby public transportation would facilitate training in independent travel.

(Discussion at the National Conference clearly showed that most attention has been given to transportation in the urban setting. Problems relating to mass transit have little relevance to many states and areas. One participant pointed out that the most ubiquitous public transportation mode was "the big orange bus" that rolls down the rural highways and roads bringing children to school. Making public education universally available to all would do much to solve the transportation problems of the rural area, this participant felt.

Participants from several of the developmentally disabled in rural states indicated that a good portion of their DD funds are directed to development of transportation in their states. One indicated that their DD Council would not approve any proposed service program that did not clearly specify how they would accommodate the transportation needs of their prospective clients.)

Public Policy

Major questions are being posed regarding the extent to which transportation systems built for the masses should be usable by those with mobility problems. This question arises because of the funds, available through the Urban Mass Transit Administration, which are being spent on helping communities develop transit systems, and the laws that govern UMTA activities.

There will perhaps be some for whom specialized services will be necessary. Should that number be kept as small as possible, or should public policy be to develop "separate but equal" systems for a substantial portion of the population, such as the aged and handicapped?

Representatives of the transportation industry have made their position rather clear. In testimony before the Senate Special Committee on Aging, Herbert Scheuer, assistant to the executive vice president of the American Transit Association, stated . . . even if urban transit bus systems could afford to make buses totally barrier-free, we would question the advisability of doing so. The goal of mass transportation is to move great numbers of people from point A to point B as quickly and efficiently as possible . . . . The problem of moving the handicapped–a very small percentage of the total ridership–is of special concern, outside the realm of mass transportation, and rather a community and welfare responsibility."

A spokesman for the Department of Transportation has been a bit ambiguous on the question of special systems. In testimony before the Aging Committee, mentioned above, John E. Hirten, Deputy Assistant Secretary for Environment and Urban Systems, responded, "We believe, within the Department, that there is a need to serve the elderly and the handicapped through a variety of methods. One method that certainly deserves consideration is a system that would enable either taxi service or minibus service to go into areas where the elderly live and take them where they need to go, that is hospitals, clinics, and what have you." [1]

One unique demonstration project developed through funding from both UMTA (DOT) and the HEW Social and Rehabilitation Service, is in the Naugatuck Valley of Connecticut. The Connecticut project is in an area in which no public transportation now exists. In developing the project, design consideration has been, first, for the needs of the aged and handicapped, and secondly, for all others. Some twenty-six local agencies are involved and supporting the project. The Heggi Training Center in Derby is selling six of the seven buses it now operates (one is being kept for emergency) and funds equal to the cost of their service are being allocated to the project for transportation of clients.

Since the project will also provide services to the public at large, it may be able to avoid the problem of "separate but equal." Already, the Connecticut project is providing useful information to other agencies in areas such as equipment design and fare collection and tracking systems.

There is no question that there is a very large public commitment to transportation throughout the country. The most obvious evidence is the presence of the Highway Trust Fund and the amount of tax monies in it. The real question, then, is determining priorities within this public commitment. Many participants at the National Conference felt that the Highway Trust Fund should be opened up to provide funding directed toward a greater variety of transportation needs. By focusing so closely on the development of more and better highways, it was felt, many needs of particular groups were submerged.

Additional questions were posed regarding the role of the Department of Transportation in meeting the needs of the handicapped and aged. Disappointment was expressed that the Biaggi amendment to the Urban Mass Transportation Act merely provided permissive authority to direct one and one-half percent of available research and capital grants funds to transportation of the elderly and the handicapped. It was further pointed out that, reflective of its name, the Urban Mass Transit Act did not provide for rural transportation and that there was, as a consequence, no major public focus on the needs of the rural areas. Any assumption that the automobile is sufficient in these areas does not take into account the specialized needs of particular individuals and groups such as the developmentally disabled.

SUMMARY

Clearly there are more questions than answers in regard to transportation and the developmentally disabled. The knowledge that is generally available relates to the urban situation, leaving the rural areas to the car pool.

Even so, there is much that can be done in terms of developing independent transportation capabilities in developmentally disabled individuals. If there is a problem that seems to range across all categories of developmentally disabled, the problem of dependency would seem to be one.

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[1] **"A Barrier Free Environment for the Elderly and the Handicapped," Hearings before the Special Committee on Aging, United States Senate. October 20, 1971. Part 3.**

On the other hand, the approaches to solving the transportation problems of the developmentally disabled seem to share many commonalities, especially in terms of the specialized system. Funding, equipment, personnel, scheduling, services, use of time, all seem to pose similar problems, whether the presenting disability is physical or mental.

Finally, the chief policy issue–transportation systems usable by all vs. "separate but equal" seems to be relevant to all with special transportation needs.

Case Management, Personal Advocacy and Protective Services

Keith Yelinek

During the decade of the 60's one of the foremost issues expressed by persons with organizations interested in the developmentally disabled person was that of educational opportunity. While educational opportunity is still a prime objective, the most frequently discussed issue at this time is that of protective services.

The desire for a system of protective services for the developmentally disabled person can best be stated as a desire for a legal and social system that will assist those persons who do not have adequate mental and/or physical capacity to direct and control their own lives, to live, grow, and develop to their fullest potentialities through the guidance and protection of another person or persons.

The goals for such a program can be illustrated by referring to the following statement from the "Task Force Report of the Wisconsin Mental Retardation Planning and Implementation Program":

> A broad program of protective services for the retarded should serve the goals of (1) securing his civil rights whether in an institution or in the community, (2) acting on his behalf in securing necessary or desirable services, (3) representing him in situations of conflict with agencies providing services or with institutions to which he is committed, and (4) managing his estate. Every retarded person who needs guardianship or protective services should have them, no matter what his age, degree of handicap, or financial resources."

The need for such a program is primarily a result of the success we have had in mitigating some of the other problems connected with developmentally disabled persons. As is frequently the case, the solution of a specific problem eventually leads to the creation of additional related problems.

In recent years, the concept of institutionalization and custodial care has given way to the implementation of community-based programs of education and rehabilitation for developmentally disabled persons in order to achieve the individual development of their capabilities. With this newly placed emphasis on keeping the developmentally disabled person within his own family unit and local community, he must be provided with guidance and supervision in those areas of living where he cannot care for himself.

While great improvement has been made in the education and training of such persons during the last decade, our society has changed so rapidly that a person who may not have required guidance and supervision in a more simple social system must receive such protection if he is to function in the social system of today.

More important, however, is the fact that the longevity of such persons is being increased and frequently they are outliving their parents and the social and economic support or guidance parents provide. Therefore, if "society" does not provide a system of protective services to replace the support and guidance of the parent or family unit, the return of the developmentally disabled person to the "community" may not be of long duration.

The purpose of this paper is to discuss some of the reasons for this change in emphasis, the role and relationship of case management, personal advocacy, and guardianship in a program of protective services and the requirements if such a program is to be effective.

At the present time, the law of guardianship is the only system available to provide protective services to the developmentally disabled person. However, dissatisfaction is being expressed that the law of guardianship as presently operating does not provide the framework that is required to develop the desired program. In order to understand the reasons for these frequent expressions of dissatisfaction we must consider the form and history of the law of guardianship in the United States.

Three plans of legal guardianship are generally provided by state laws. One extends to the person of the individual under guardianship (guardian of the person), another to his property (guardian of the estate) and a third to both the individual and his property. A *guardian of the person* is one appointed by the court to have the care, custody and control of the person of a minor or an incompetent. In general, the term refers to the person having the right to make major decisions affecting a ward, including the right to consent to marriage, to enlistment in the armed forces, to major surgery, and to adoption or to making recommendations as to adoption. The legal custody of the ward is given by the court to the guardian of the person. A *guardian of the estate* is one appointed by a court to have the management of the estate of a minor, an incompetent or a spendthrift. A guardianship of the estate of any person, once granted, extends to all his estate and excludes the jurisdiction of every other court. Estate refers to the interest which one has in land and other property, such as a bank account, bonds, inheritance, etc.

The underlying theory and philosophy of guardianship is derived from two legal systems, the Roman and English. Under Roman law, guardianship was viewed as a concept of blood relationship—a continuation of the power of the head of the family over his descendants. The law of guardianship, derived from the English common-law rules, grew out of the feudal law of the land with its system of land tenure and was essentially an institution existing in regard to the propertied classes. Early English law had many different types of guardianship but on the death of the father, the type of guardianship which resulted depended on the nature of the property. Unpropertied children were substantially ignored by the law of guardianship.

In those states that have a guardianship law derived from English common law, which is the majority of the states, the specific provisions of that law are concerned principally with property matters. Therefore, the law of guardianship as applied by the courts in these states has followed a fiscal approach rather than a social approach. This emphasis on property values over human values is one of the major reasons for the dissatisfaction with the law of guardianship as a delivery system for protective services.

Under the law, the courts have a twofold function in guardianship. The first is a judicial one. It entails the determination of the need for guardianship and when there is need, the appointment of a suitable guardian over his person, estate or both.

The second function of the court is an administrative one. It entails the maintenance of a proper record of the individual wardship and continuing supervision over the guardian to make sure that the individual's interest and welfare are being served at all times. The courts carry on this administrative responsibility through the process of appointing, supervising and discharging guardians.

In selecting a guardian, the courts place reliance on the principle of kinship and in the device of bond and surety for holding him to his responsibility. Social standards and social-study procedures are almost never used by the courts in discharging these responsibilities.

In addition, the courts conduct practically no follow-up of the person placed under personal guardianship unless or until a petition for the removal of the guardian is presented. Except for the requirement of bond, referred to previously, the guardian of the person is completely outside the supervision and control of the court appointing him. The guardian of the person is under no requirement to submit a periodic accounting of his stewardship. The court generally maintains no contact with him and for all practical intents and purposes, permits personal guardianship to be exercised at the guardian's pleasure.

However, the guardian of the estate is subject to several legal controls by the court. He must file a bond and periodic accounts, usually on an annual basis. He must submit for court approval his plans to invest, sell or disburse the assets of his ward's estate.

It is readily apparent that the law of guardianship, as developed in the United States during the last two hundred years, is primarily directed to the protection of property rights. The interests of the person are considered only infrequently and in those instances it is primarily through the desire to protect third parties from the person under guardianship.

As the disabling conditions of the developmentally disabled will vary in type and degree, the needs of such individuals will also differ. Some individuals will require fulltime supervision while others will only require occasional help with minor problems and decisions. Also the needs of any one individual may change during a lifetime. Therefore, in seeking to provide a continuum of protective services tailored to the individual needs of the developmentally disabled client, the delivery system for such a program must be flexible enough to respond to these varied needs.

The law of guardianship does not provide for this flexibility because a guardian cannot be appointed for a person until such person has been declared incompetent by a court of law. Such a person not only suffers from the stigma of being considered incompetent, he loses certain civil rights–such as the right to marry and the right to contract.

The present legal standards for determining whether a person is "incompetent" do not recognize degrees of incompetency nor do they recognize the different types of physical and mental impairments. Therefore, we are faced with an "all or nothing" situation whereby we cannot obtain the protection of the guardianship system if a person is not legally incompetent.

It is obvious that there are many persons who could benefit from a program of protective services, but are not "incompetent" and should not suffer the loss of their civil rights.

As a result of this inflexibility in the guardianship system and the previously mentioned inadequacies, alternative systems have been proposed to provide the desired individualization. Proposals have been made to establish a legal status of "prolonged minority" for persons who could benefit from a protective services program but are not incompetent by legal standards. Such persons would be considered as minors, and therefore subject to all the protection of minority status, even after reaching majority. No determination of incompetency would be required to impose guardianship. At this time no states have enacted this type of legislation; however, such a system is operating in Sweden and Belgium.

In addition to the possible changes in our legal system, several programs have been developed which provide for systems of advocacy that are based on a non-legal rather than a legal basis.

Under the concept of Case Management a social worker relinquishes his traditional role with a direct service agency and assumes the role of advocate for a client. It is the social worker's responsibility to secure the appropriate services for his client throughout the client's life cycle. To be effective the social worker must have organizational autonomy from a particular service agency and the ability to obtain the desired services on behalf of the developmentally disabled client. The Developmental Disabilities Act, P.L. 91-517, refers to this new role of a social worker as the "Follow-along Service." The State of Rhode Island has already implemented such a program but it has not been in operation long enough to determine its level of success.

A Personal Advocacy System seeks to provide a developmentally disabled person with a friend (i.e. advocate) who will assume the responsibility for protecting the interests and rights of that person.

In most cases the personal advocacy systems that have been implemented are informal and voluntary. However, a Personal Advocacy System was recently created in the State of Ohio as a supplement to the "State Protective Service System" through the coordinated effort of the Ohio Association for Retarded Children, the Epilepsy Foundation of America, the United Cerebral Palsy Association of Ohio, and the Ohio Developmental Disabilities Council. This system is unique in that it is formalized and has been implemented on a statewide basis. A synopsis of this program is attached as Appendix A to this paper.

The Case Management and Personal Advocacy Systems do have an important future role in providing a program of protective services. However, it is this writer's opinion, that their effectiveness is limited because the supervision of the "advocate" is conducted by an entity that derives its authority from the voluntary assumption of responsibility rather than a statutory responsibility. It is also my opinion that without a statutory responsibility it will be difficult from an "advocate" to discharge his responsibility to his client with any degree of authority.

It is my opinion that a revision in the legal concept of guardianship holds the best promise for an effective delivery system for a program of protective services. The required components of such a system were best expressed by the participants in the "Symposium On Guardianship of the Mentally Retarded" sponsored by the International League of Societies for the Mentally Handicapped in San Sebastian, Spain in 1969.

Some of the conclusions reached at the Symposium are as follows:

> . . . that guardianship should be viewed positively as a means of implementing rights and opportunities, with as much participation by the retarded as is practical in all decisions affecting him.
>
> . . . the participants also believe that, in addition to the institution of formal guardianship, a parallel service of personal counseling is required, available to mentally handicapped persons who, if they receive appropriate guidance and advice on a continuing basis from a counselor who has earned their confidence, may not require formal guardianship.
>
> The fact that a retarded person is receiving, or has received services from a specialized agency for the retarded (school, workshop, residential facilities, etc.) or has been diagnosed as retarded for medical, educational or other treatment purposes, should not be construed as necessarily indicating that he needs a guardian.
>
> The retarded adult should be permitted to act for himself in those matters in which he has competence . . . a person whose mental retardation is characterized by impairments of social competence which are partial should enjoy a partial guardianship specifically adapted to his strengths and weaknesses.
>
> The participants in the Symposium strongly recommend, therefore, that the professional evaluation of an individual's competence and the extent and character of his need for guardianship not be entrusted, as in the past, to a physician or psychiatrist alone, but that a multidisciplinary team of experts, with experience in mental retardation, be charged with this responsibility. Such a team would include–in addition to a psychiatrist–a psychologist, a social worker, an educator and other trained observers of social behavior.
>
> . . . that the need for guardianship be re-evaluated from time to time, it is recommended that the same or similar multidisciplinary team be convened for this purpose.
>
> As one of his most important functions, the guardian should select and mobilize appropriate community resources, drawing on both the generic and specialized services for education, rehabilitation, health care, recreation, employment, social services and specialized day or residential care, as needed.
>
> As appropriate in each case, he should encourage initiative on the part of the retarded adult, complementing this with action of his own, as necessary, to assist the retarded person to secure access to the program most likely to benefit him.

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> The participants agreed that there must be . . . adequate machinery for the effective supervision of the guardian, individually and collectively, and for reinforcing the system of guardianship, through constructive review.
>
> . . . it is unreasonable to expect the courts themselves to engage in the kind of constant monitoring of the systems which the participants envision as necessary if the benefits of guardianship as heretofore outlined are to be realized.
>
> In keeping with their sense of the primacy of personal considerations, the participants were of the opinion that a report on the ward's personal well-being and programming for the year should also be expected.
>
> However, better orientation of judges will not suffice in itself. The courts or tribunal will need the support of a well staffed agency,–public and permanent–which, among other things, has the power and duty to bring before the courts some of the information on which court action should be taken.

If the principles stated above are incorporated within a revised law of guardianship, the resulting legal structure should support the system of protective services that we all desire. However, I must point out that merely revising of the law of guardianship without implementing the accompanying social programs will not enable us to reach our desired goals. Therefore, it is imperative that the several components of the desired system of protective services be developed and implemented at the same time.

Attached as Appendix B to this paper are selected extracts from the comments of the participants in the workshop session on "Case Management, Personal Advocacy and Protective services" at the National Conference on Developmental Disabilities, held in Washington, D.C. on November 17, 1972, where this paper was originally presented.

Appendix A

PERSONAL ADVOCACY SYSTEM FOR OHIO

Philosophy and Rationale

The Personal Advocacy System of Ohio is undergirded by certain basic principles. We feel that every citizen regardless of the severity or multiplicity of his handicap, has certain inalienable rights–human and civil. Certain of our handicapped citizens are not capable of exercising these rights–depending on the situation, the life experiences the individual has had including his opportunities to make decisions, the impairment in his adaptive behavior, and his physical and/or mental status.

Since no agency or individual is endowed with Godlike Powers to know at all times and in all situations "what is best" for another individual, we feel that all judgments and decisions of agencies and individuals managing handicapped individuals should be audited and reviewed regularly by someone outside of the system or service.

A personal advocacy system has a two fold responsibility: it must provide individuals in the system with a concerned friend on a personal basis, and it must watchdog the delivery of services system to see that the individual gets those services which he needs.

We feel that such a service is best provided by a voluntary or nonpublic agency which understands the total needs of handicapped individuals and their families.

Definition of Personal Advocate

A personal advocate is an individual who assumes a responsibility for looking after, as if they were his own, the interests and rights of a handicapped individual.

Organization and Strategy Plan for the Personal Advocacy System

The proposed Personal Advocacy System operates as a supplement to the State Protective Service System which had a target date for initiation of July 1, 1972. As proposed it was to bring the three main voluntary agencies together into a statewide plan for advocacy on a cooperative, comprehensive statewide basis under the following guidelines:

1. The statewide system would be operated in a Consortium Board appointed by the DDA Council. The Board would be composed of representatives from the *Epilepsy Foundation of America,* the *Ohio Association for Retarded Children,* and the *United Cerebral Palsy Association of Ohio.*

2. The State Office was to be based in the Headquarters of one of these three Agencies or office of Ohio Developmental Disabilities Council.

3. The office would be staffed with a Personal Advocacy Coordinator, Administrative Assistant and a Clerk-Typist. Job descriptions for these positions will be in conformance with recommendations of the Personnel Committee of the DDA Council. Staff will be employed by the Consortium Board of Directors.

4. Each voluntary agency wishing to participate will be asked to appoint a Standing Advocacy Committee and assign responsibility for Advocacy functions to either a staff member or the Chairman of the Advocacy Committee.

5. Each participating agency will be required to have the staff person or the Chairman attend training sessions at regular intervals.

6. It will be suggested that the University Affiliated Facility, under contract with DDA Council, will conduct at least on a semi-annual basis, training sessions for Supervisors of the Advocacy Programs and for Personal Advocates.

7. Advocates so trained will be designated as "Approved Advocates." Participating Agencies will be designated as "Approved Participating Agencies."

8. District Offices will be required to inform applicants for either Protective Services or Case Management Services of the Advocacy Service available to them.

9. Names of clients wishing to participate in the Advocacy Service will be forwarded to the District Coordinating Advocacy Committee.

10. Advisory Committees will be Standing Committees in each of the District Citizens Councils which are to be reactivated. Such District Coordinating Advocacy Committees should have representatives from each of the participating agencies.

11. In addition to clients referred to them by the District Offices, each Participating Agency will also be free to "case find" or seek out other individuals within their target area for whom Advocacy Services are appropriate.

12. DDA Council on an ongoing basis will hopefully fund both the Advocacy Coordinator at the state level and the training workshops.

Roles and Responsibilities of an Advocate

1. Be a concerned friend to a handicapped individual.
2. Maintain promised commitments to this individual.
3. Attend training sessions.
4. Know the personal and program needs of his protege.

5. Be familiar with the prescriptive program plan for this individual.
6. See that this plan is followed.
7. Raise questions with the Staff Person or Committee Chairman assigned responsibility for the Advocacy Program when the individual's plan does not seem to fit or is not being followed.
8. Keep in touch with professionals serving the handicapped individual, in the manner that a family would keep in touch with a child's teacher.
9. Be acquainted with the other individuals in the environment of the handicapped individual, for example, landladies, policemen, shopkeepers, etc.
10. Know resources in the area.
11. Know procedures for intervention.

Responsibilities of the State Level Advocacy Coordinator

1. Be directly responsible to the Executive Committee of the Consortium Board.
2. Coordinate of Personal Advocacy Program activities between State, Regional and Local Agency levels.
3. Develop guidelines for operation of the program at all levels.
4. Develop uniform systems, procedures and forms for both agencies and advocates including certification procedures.
5. Assist in developing and conducting a training program for Supervisors and Advocates.
6. Be responsible for public relations and education programs and providing information services about the Personal Advocacy Program.
7. Consult with agencies, supervisors, district directors, and workers.
8. Assist in matters of litigation and intervention.
9. Prepare progress reports on the program.
10. Work with coordinator–District Citizens Committee in coordination of programs.

Appendix B

Participant Comments

Workshop Session on
CASE MANAGEMENT, PERSONAL ADVOCACY & PROTECTIVE SERVICES

National Conference–Developmental Disabilities

THE CHAIRMAN: "On the panel we have Howard Rosen, Lawrence Kane, who's a lawyer and member of the President's Committee on Mental Retardation, Ardo Wrobel, who is the Director of the Division of Mental Retardation in Minnesota, and our topic writer for today's conference, Keith Yelinek. I am your Chairman, Dennis Haggerty."

MR. YELINEK: "There are several questions I would like to pose for our participants and for you in the audience. How does citizen advocacy and personal advocacy differ; how are they alike; what are the advantages and disadvantages of each of these systems? What future role will citizen advocacy or guardianship play in the development of a protective services system? Who should have the responsibility for the follow-up supervision? Should it be a court responsibility? Should it be an administrative agency? Or, should it be strictly a voluntary organization's responsibility, such as the local ARC or other public service agency? And lastly, when should either or all of these programs be implemented for the benefit of a developmentally disabled individual?"

CHAIRMAN: "Given an actual commitment as stated by the President in November of 1971, a reduction of the complement in the state schools and hospitals throughout this land of a significant percentage given that and given the fact that the heretofore residents are going to be in communities, you can see how timely the questions posed by Mr. Yelinek are.

"Now, our resource personnel, Mr. Rosen, Mr. King and Mr. Wrobel are not necessarily the respondents to the paper that has been presented. They are just that, resource personnel, but they may respond as they wish and in their response or in their comments, they may want to agree with or disagree with or present additional thought-provoking comments on how to manage and how to deliver protective services in the community. I'd like to start off with Mr. Rosen."

MR. ROSEN: "I would like to respond to your third question in terms of who will have the ultimate—or who should have the ultimate responsibility. I chose this one because I feel it's the easiest for me in my framework, because I come from a state where a protective services law was recently passed—and that's Colorado. In Colorado, the responsibility for protective services is with the Department of Social Services. By placing protective services in the Department of Social Services, the funds which the State Legislature made available to begin this small experimental program can be matched with Federal Social Service Funds. It's extremely advantageous to the state because . . . out of $50,000 it makes $200,000. In addition, the State of Colorado . . . felt that most of the people who require protective services are people who are eligible for services from the Department of Social Services in terms of their income, which is quite limited . . . . I could see the Department of Social Services in this state having the ultimate responsibility for protective services for individuals who need this service."

CHAIRMAN: "Mr. Kane would you comment."

MR. KANE: ". . . to have an effective guardianship on a citizen advocacy program, you've got to separate that entity, and I look upon it like a little agency of itself, a new thing to be created; but it should be independent of other agencies in terms of its funding . . . . they would pick up in guardianship those that needed it and only to the extent that they need it . . . . the probate court could then be, as it traditionally has been, the entity to which this agency reacts in terms of periodic review and the sophistication of services that the guardianship agency is to look for, and advocate for, and find for each retarded person.

"The retarded person . . . should be walking around with rights . . . he needs a Social Security system which serves everyone that has a handicap up to a level that they could live with and live on, if necessary; and a national system of health insurance which would be available to every handicapped person . . . . The guardianship agency sees that those rights are realized and implemented; and, if you will, the probate court is kind of a super-structure that sees that it all works out. And you know, it may be terribly simplistic to put it this way, but if we have a sensible Social Security system, and if we had a sensible national health insurance program which dealt with the handicapped . . . many of our problems would go away. You see, as we talk about it now, we can dream up and conjure up and structure and diagram endlessly all kinds of structures for guardianship . . . ."

MR. WROBEL: "I would like to examine several of Mr. Kane's comments because I think that he was talking about the balance for the polarized system of . . . guardianship from a legal framework, and I think you are saying it should be outside of the agency system . . . .

"I would like to cover maybe a little bit about what you said in terms of what there is in this whole spectrum . . . . It covers more than the legal guardianship of a person. I think there is the social . . . if the agency itself does not have a commitment toward any system, . . . to deal with matters of rights of the individual and delivery of them, then I'm just afraid that . . . we could be setting up an adversary kind of situation. I would like to see some concentration on the idea that the agency itself and the people who work in this agency have the ability to develop a sense of advocacy for the individual.

"In Minnesota we just established a department policy concerning advocacy; we're working on the procedures that would be involved. I would like to stress that, at least from my point of view, I think that the agency also is an advocate, in a sense. If we can give staff people in the facilities a sense of also being advocates of the individual, we may help to bring about some of the efforts from the outside, and from the public point of view. So, I would rather see it not so much a polarized system but rather the concerted effort to get the system to respond.

"I think Ohio has set up a rather responsible way of handling this: that is, on the regional basis there would be a case manager who would be part of the agency.

"It is set up so that when there is controversy and when there is difference of opinion, it's resolved around the person rather than the traditional way of doing it where the parent tries to fight the institution or the superintendent or the agency . . . ."

MR. KANE: ". . . I still see the role of the advocate as a separate thing. Maybe it does polarize a bit, but that's how we're making some progress. I have more confidence in the probate court than I would have had a few years ago because of the dynamic things that are happening in constitutional law which affect the legal rights or constitutional rights of the mentally ill and mentally retarded. Almost every month we get a new decision which is even more sophisticated and more clear about the due process rights of the handicapped. Whatever our bad experience has been with courts over the years, it is changing and it's changing almost every week."

CHAIRMAN: "Could I just pose a question and ask someone in the audience to respond to it, other than the resource people. Given a situation where a retarded individual is moving from an institution and needs some services but he is not yet to the point of competency so he would have to have a guardian appointed for him. Given that, how do you see the role of a personal advocate who is not accountable on a periodic basis, either for what monies he might handle or for whatever personal attention he gives the retardee, how do you see that working as drawn from your own experiences, you know, as volunteers."

MR. BECKETT: "Bob Beckett, Ohio, Belleville Disabilities Council.

"I think you answered your own question. I'm a consumer, a volunteer, and a volunteer is a rather fickle person .... So, I think what you're saying here is: Do you think that an advocate should have some bindings as to his action? And I would say "yes" because when an individual is looking after another individual I think it should be a consistent and a rather flexible thing as far as what his duties are.

"... I think that there have to be some ground rules and I think they have to be legal, so that we are bound to really doing the job."

DR. POMEROY: "I'd like to comment. Jim Pomeroy from Oregon Bureau of Mental Retardation.

"I think we have a responsibility to teach the retarded to be his own advocate and I think that many of them can become their own advocates with our assistance; and they haven't been pushed in this direction very much and I think many of them are capable of being their own advocate, standing up for their rights.

"When you get around to it, I would like to have some discussion on his rights versus privileges. We talk about rights in general and I think maybe we might be moving too fast sometimes–that we have a responsibility to teach them their responsibility before we stress rights. And we have, as their advocates, a responsibility to them to define for them what their privileges are just as we do our own children. We don't give them their rights until we think that they have learned to accept this as a responsibility."

CHAIRMAN: "Well, could I just pose a query to that. Don't you think in adopting that attitude, given the gradations of deficiencies of this group, that some would opt for not giving rights unless the handicapped person met criteria which would be difficult to meet under most circumstances?"

DR. POMEROY: "For example, the right to vote. I think that they have to know what it means to vote and that they have to be able to exercise sufficient judgment in voting."

CHAIRMAN: "But are you not now talking about–in that example you brought up–the old-time, dishonored now, standards of literacy which were used to keep people from voting?"

DR. POMEROY: "No, I don't believe I am. I think that they can be taught how to go down and register; they can be taught about the reading and understanding of what the candidates represent and what they are voting for.

"And driving isn't a right. Driving is a privilege. And you know that, and I think many other things that we talk about as rights are not rights but privileges. They have to be earned."

CHAIRMAN: "You would agree, wouldn't you, that we wouldn't apply different standards to a handicapped person?"

DR. POMEROY: "No."

CHAIRMAN: "We would apply the same standard to all."

DR. POMEROY: "That's right."

CHAIRMAN: "Okay."

DR. POMEROY: "But I'm fearful that we might be trying to broaden that standard . . . ."

MR. ORWIG: "I'm George Orwig and I'm Chairman of the Pennsylvania Council and I happen to be an attorney. And my main interest is epilepsy. This discussion has pretty much concentrated on the field of mental retardation and, of course, we're talking about developmental disabilities, which is more than just MR. You cannot have a common standard that you apply to all DD's if you are going to talk about cerebral palsy and epilepsy in addition to mental retardation.

"The type of advocate program that you need for the epileptic who is not mentally retarded–and most of them are not–is entirely different than the type of advocacy program you have to develop for those who are mentally retarded. So, let's not be discussing standards that you feel you can apply across the board because with cerebral palsy, and epilepsy–true, we have some that are all three–but for those who are not, the type of advocacy that they need is completely different from what the MR would need. We can't just lump them all together."

MR. THRONE: "I'm John Throne from Kansas. I share Mr. Kane's dubiousness about leaving to an agency the responsibility for advocating what it's responsible for doing; but I don't see the polarization between his position and Mr. Wrobel's that seems to be taken for granted. Even in Ohio, as I understand it, where this operation involves three people, the personal advocate is not a member of the state agency, as I recall. He doesn't work for the state. He is just as much a private citizen as you would have him be; so I really think that there is potential, at least, agreement between you two gentlemen on what you are talking about. It reminds me of a little project we are undertaking in Kansas . . . . What we have in mind is having a volunteer from the community, probably say an ARC representative, who will volunteer as a citizen to serve as–we don't exactly know what the term is–community advocate, personal advocate or whatever, in behalf of an institutionalized resident at the time of institutionalization . . . . He will serve on the planning and, insofar as is possible, on the training and implementation committees that work with this patient right from the beginning and then follow him out into the community and continue to serve as his advocate in the community, having prepared the way in the community well in advance of his discharge."

CHAIRMAN: "Who appoints who?"

MR. THRONE: "Well, we thought we would have a pool and, using certain criteria, we would call upon volunteers. For example, if we have a resident from Dodge City, Kansas, we would look on our little map and we would call up a couple of people in that area who have indicated that they would be interested in serving this function and ask them if they would volunteer to serve in this capacity.

"Now, strictly speaking, I believe that the person would have to be an appointee of the institution who has legal guardianship over the child.

"What we are interested in avoiding is breaking down the four of our institutions into what amounts to regional institutions. I don't see that as much of a gain. And I see a lot of state programs in danger of doing just this. I don't really see that that will be progress."

CHAIRMAN: "Just a thought on this subject. Unless you have some way to monitor the criteria for how decisions are made for an individual who may be handicapped, you may have some weird decisions . . . .

". . . in a lot of my conversations with people, I find that mothers of boys don't want their boys sterilized, but mothers of girls want their girls sterilized and you might get a personal advocate who would be in one category or another category giving his decision or her decision."

MR. THRONE: "Well, but you have these kinds of disagreements among staffs in institutions or in agencies and all we're proposing is that added to this mix would be some personal advocates who presumably–sure, they have ideas of their own about just the very point you made–but are not beholdin', I mean they're independent presumably. They come as close as you can get in principle to being surely interested in the resident and his interests rather than in serving an institution's best interests."

MS. KINDING: "Columbus, Ohio. But as we look at the dynamics of the movement toward a personal advocacy program . . . I think that we're now going to literally institutionalize this citizen advocacy thing, so I don't have to sit out here alone. I need help. I need to be able to call on a structured system that says, 'I've got the sanction and authority to put some pressure at certain points to get a job done.' Nor do we let this thing hang out in mid air. We have to have a point of entry for the advocate; and in our case in Ohio, that point of entry is going to be that case management protective service module. No citizen advocacy program can function unless we can get the pressure point and get the job done and get the change."

CHAIRMAN: "In Ohio, does the case manager answer to the Division of Mental Retardation? Does he react to that structure?"

MS. KINDING: "He does. At this point in time. This will be decentralized and the only hope we have here again, you know that the guy that gets the money is monitoring himself which is not a good system. On the other hand, the only counter-balance we can have today is to develop the citizen advocacy components strong enough so that the pressure (just as the pressure of the parents years ago initiated this whole movement) can be brought to bear on that module. Now, on top of that we are also moving towards the re-establishment of citizens' committees, and within these citizens' committees there hopefully will be task forces with special interests on residential services, citizen advocacy, etc. You go for a very different group of people in a community to consider the development of a residential program than you do for a citizen advocacy program. And we might not wear out so quickly if we had a few successes with our advocacy. In the past this has been very difficult."

MR. ORWIG: "I wanted to comment. You raised the questions earlier about what kind of binding arrangement you had with the citizen and, it seems to me when I think about this idea, that the more binding you try to make some kind of arrangement, the more difficult it's going to be to get people to be citizen advocates. In any event, you're practically going to have to insulate it with some kind of a good samaritan statute. I would never be one unless I was insulated. Particularly in my position as an attorney I just wouldn't because the kinds of people that you would want to be citizen advocates, you know, are not perfect; nobody's perfect, so you're taking that risk today. In this litigation conscious society in which we live today, you're going to have that problem with citizen advocates. They're going to make mistakes–not intentionally, but unintentionally. And, families are going to come forward at the urging of their department of welfare case worker to seek redress–and I can just see the problems in this kind of an institution. And those people are going to be insulated by a good samaritan statute; I'm just absolutely certain of it. I would never personally want any part of a citizen advocate program unless that were an integral part of it."

CHAIRMAN: "Given the fact that you'd want this good samaritan statute, which means if I act I want to be protected from what I might do wrong, where do you then draw lines because you do have people who are working in institutions now seeking that kind of insulation themselves?"

MR. ORWIG: "Well, in many instances they have it."

CHAIRMAN: "But where do you draw the lines? Where do you stop the accountability? I grant you have a problem of finding the bodies and doing the job."

MR. ORWIG: "Well, I don't think any good samaritan statute insulates you from wanton and willful wrongdoing."

MS. KINDING: "We don't have the drive of the parents any more. We don't have the concern of the individual or the friend or the aunt or the uncle who hit hard for a long time. And what we're really doing is coming up with some other system of bringing about the same pressure that we had with parents. But just as parent, we're satisfied with some levels of care, some services; they became complacent and have moved away and I challenge anyone in the United Cerebral Palsy, Epilepsy or the ARC's to show me the kind of membership, parental membership in their agencies, that they had ten 10 years ago. They're having a heck of a time surviving and we're now going to take federal money and put it in there and say, "Now, we'll set up a kind of a system to bring it back, to bring the same motivating pressure back."

Part VII
Future National Strategy

Editor's Notes

No publicly funded program exists in a vacuum; it is vulnerable to shifting public attitudes and alterations in policies and priorities resulting from changes in administration and in the composition of legislative bodies.

As a small, new, and thus far, underfunded federal program, DDSA is particularly susceptible to the program and funding priorities established by the current Administration and the Congress. In addition, in recent years it has become apparent that the attitudes of the judiciary—particularly the federal courts—are likely to have a major bearing on future directions in programs for the developmentally disabled.

Daniel M. Sprague explains the purposes and provisions of a piece of legislation which incorporates the principles of one of the Nixon Administration's highest priority efforts in the area of human services reform. An integrated approach to human services and decentralization of decision making responsibility are the keynotes of the Administration's Allied Services legislation. The author compares the intent of the Allied Services Bill and Developmental Disabilities legislation and concludes that "in many respects the Developmental Disabilities Act can be viewed as a mini-Allied Services Act for a particular group." He outlines six major features of the pending Allied Services bill and suggests ways in which enactment of this legislation would serve the interests of the developmentally disabled.

In drafting the original Developmental Disabilities legislation, Congress recognized the need to reserve a small percentage of available funds to stimulate needed changes in techniques and approaches to delivering services to the developmentally disabled. For this reason the Secretary of Health, Education and Welfare was authorized to set aside up to 10 percent of Title I appropriations for projects of "special national significance." George N. Bouthilet describes the manner in which the priorities for use of initial national significance set aside funds were reached and outlines the purpose of projects already approved and those areas in which grant applications are being sought. He also reviews present efforts on the part of the federal administering agency to evaluate the impact of the Developmental Disabilities program.

Litigation has emerged in the past few years as one of the most promising new avenues for reform in current practices and patterns of delivering services to the developmentally disabled and other handicapped citizens. Stanley Herr analyzes some of the long range implications of recent court decisions involving the rights of handicapped children and adults. After reviewing relevant trends in judicial thinking and describing the federal court's decision in the District of Columbia "right to education" suit, the author predicts that the courts will continue to take a more active role in safeguarding the constitutional rights of developmentally disabled persons.

The Allied Services Bill and Its Implications for Developmental Disabilities

Daniel M. Sprague

INTRODUCTION

On May 18, 1972 President Nixon sent a "special message" legislative proposal to the Congress. This bill—the Allied Services Act—was developed by the Department of Health, Education and Welfare as a vehicle to encourage states and localities to develop partnership processes whereby human services programs could be better integrated toward the attainment of certain antidependency goals (see Appendix A for a summary of the provisions of the proposed bill). The Act was referred to the Labor and Public Welfare Committee in the Senate and Education and Labor Committee in the House. No action was taken on the Bill in the last session of Congress.

The Administration did not expect any action on the Bill but sought to submit it during this past session in order to stimulate a nationwide dialogue on the problems inherent in the present categorical services configuration; and, as part of this debate, to promote discussion of the merits of the Allied Services approach as a way of adding a horizontal, integrative dimension to vertical, unconnected grant-in-aid service programs. The Allied Services Act will be rewritten by HEW and reintroduced by the Administration for early consideration in the upcoming session of Congress.

PURPOSE

This paper has been prepared for discussion at the Allied Services Act workshops of the National Conference on Developmental Disabilities. The purposes of the paper are:

(a) to explain briefly the context in which the Allied Services Act is offered and to outline its basic provisions; and

(b) to suggest the ways in which the Act would work to supplement and strengthen the mission of the Developmental Disabilities program.

Hopefully, this paper and the workshop discussion of it will stimulate further awareness and analysis of Allied Services across a range of developmental disability interest groups and professionals in order that HEW may benefit from their ideas on how best to improve the Bill.

DISCUSSION

The Rationale for an Allied Services Approach

The Allied Services Act is the outgrowth of a two-year analysis of the 280 services programs of HEW as viewed from the federal overview perspective and the client contact point of services delivery.

When looked at either from the federal or the local ends of the continuum, the existing pattern of services delivery is inefficient and ineffective.

For the past forty years, as the social consciousness of the society increased, Congress passed particular program laws to respond to particular human conditions. The result of this well-intentioned governmental response is the 280 social, health and educational service programs currently administered by HEW. Each program has a special target group and/or programmatic mission which is intended to be served through its own set of highly prescriptive statutory and regulatory rules and delivery routes.

To give some idea of the complexities of this network of authorities, there are 1,200 pages of the Code of Federal Regulations devoted to these service programs. And, for each page of regulations, there is an average of 10 pages of interpretative guidelines. The regulations of one program frequently conflict if not directly contradict those of others.

In addition, certain statutory requirements result in highly redundant and costly practices. The single state agency statutes mean that the federal proliferation of administrative units must be replicated at the state level. Some states have as many as sixty separate program administrations. In one community in the Mid-West seven different health grants from seven different federal programs led to the creation of seven different governing boards with overlapping membership and charters. (The funds awarded under these grants represented 75% of the federal discretionary "assistance" dollars spent on health in this metropolitan area.)

In short, this highly prescriptive and specialized system of services is inherently fragmented and ill-conceived from an administrative point of view.

This problem is compounded at the client level. Surveys show that eight of every ten HEW clients have multiple rather than singular service needs–not a wholly illogical circumstance when one considers the fact that the typical HEW client is a person falling outside of the economic, educational and social mainstream of the society.

Unfortunately for all concerned the existing configuration of services delivery is ill-adapted to the multi-problem phenomenon. The following case will make this point clear.

A sick and discouraged mother of four children from Arkansas was abandoned by her husband; she is herself illiterate. Two of her children are sick with the flu, another cuts her hand on a rusty nail, and the mother has a painfully impacted tooth. So she goes to the public health clinic, which refers her to a university medical center because the extraction in the center is not covered by Medicaid. The daughter with the injured hand is taken to a different clinic, where the diagnosis is covered by Medicaid, but not the prescribed penicillin. The two sick children are referred to a private doctor who charitably treats them with sample drugs. Then, for her basic needs, food, shelter and clothing she deals with the county welfare agency. To have any hope of improving her dependency condition, she must turn to the local educational system for assistance in overcoming her illiteracy. The State employment agency is the source of job training and placement, and still another agency may be necessary to secure day care for her children if she gets a job.

This case is not an atypical example of the clients who need HEW help; nor was the service experience she had atypical of what happens every day in communities across the country.

Only last week I came across a case which will be closer to your own interests. The case was brought to my attention by the Mayor of Chattanooga. It has to do with a welfare mother of four children who had been served by nine different community agencies over the course of six years. The case was discovered through a newly installed computerized information system shared by some 300 agencies. None of the agencies which had provided some service to this woman had ever given her a physical exam. A physical examination was recently ordered and the examining physician told the Mayor that the woman was partially retarded as a result of slight neurological damage. He went on to say that this particular problem could be alleviated by the application of a drug antidote.

The obvious problem here was that there wasn't enough emphasis on fundamental preventative screening and problem diagnosis. As a result, different agencies provided emergency services to treat her symptoms but no one sought to find the root causes of her condition. It would make little sense for every agency to have its own diagnostic service. This would be very expensive and if each operated its own diagnostic service it probably would not be comprehensive enough.

If this woman had had access to adequate screening and diagnostic procedures she could have been restored to normal and productive functioning many years earlier instead of being a victim of welfare status and a drain on taxpayer dollars through years of piecemeal services provided by separate agencies.

It is the above sort of problems at the federal, state and local level which the Allied Services Act seeks to overcome. The Act is a first step toward the evolution of a state and local human service system in which service agencies have common geographic boundaries, a common set of goals and the necessary tools–waiver authorities, start-up planning and administrative grants, the some priority setting flexibility–to implement new integrated service systems. Such service systems would be accountable to the electorate, to the client and to performance standards.

Under the leadership of the Governor and with increased involvement of chief elected local officials or combinations thereof, the Allied Services Act is intended to supplement rather than supplant existing categorical programs. It is an attempt to build upon the commonalities of service programs rather than feed on their categorical distinctions.

The Implications of Allied Services for Developmental Disabilities

In many respects the Developmental Disabilities Act can be viewed as a mini-Allied Services Act for a particular target group. For example, the prime concepts of P.L. 91-517 are "the development of comprehensive services for the developmentally disabled through the combination and integration of the efforts of both specialized and generic services of several state agencies representing diverse areas such as health, welfare, education and rehabilitation, without imposing a set pattern of services on any one state."

This concept is totally consistent with what the Allied Services Act would promote except that Allied Services is more broadly concerned with human development and dependency across a somewhat broader set of service areas.

Allied Services like Developmental Disabilities does not prescribe any single model or pattern of service delivery across states. It does require that human services planning and delivery *processes* be established but leaves the implementation of the integrated services plans to the states and, through them, the localities that participate in these processes.

The nine specific programs which must be taken into account in the state plan under P.L. 91-517 are principally those which would be embraced by the Allied Services Act in any given state, with the public social services program being a mandatory participant.

In addition to the conceptual similarities between Allied Services and P.L. 91-517 there are several other HEW legislative authorities which contain "comprehensive, integrative" language. The new amendments to the Older Americans Act and to the Juvenile Delinquency Prevention and Control Act are such examples.

Perhaps the most important single feature of the Allied Services Act is the emphasis it places on the direct involvement of chief elected officials, particularly the Governor, in structuring and overseeing integrated services processes at state and local levels. This coupled with the prerequisite steps of establishing coterminous sub-state service boundaries and of conducting needs assessments and services inventories gives the Allied Services Act a basic authority which logically should lead to substantive integration as opposed to traditional forms of coordination – usually very limited in nature – across complementary but usually competitive agencies. To understand precisely what the features of the Allied Services Act are which would serve to strengthen substantially the ability of programs, such as Developmental Disabilities, to perform their particular missions the following points are presented.

1. Involvement of Chief Elected Officials at State and Sub-State Levels.– Some single unit–"the buck stops here" decision-maker–must be given the authority and responsibility necessary to make integration work. In this way, peer agencies will not be left completely on their own to coordinate only on the basis of what they exclusively perceive in their best interests. (Forty years of experience suggests that this form of integration does not work very well.) What we are seeking is a participatory process in which different providers and elected officials sort out and agree upon more adaptive and cost beneficial ways to organize human services resources. An additional rationale for designating the state chief elected official as the lead decision-maker is that he has the power to implement prerequisite steps for integration by executive order. Point #2 is such an example.

2. **Coterminous Service Boundaries**–It is axiomatic that integration of programs take place across agencies having common boundaries. (Those who have attempted integration at the sub-state level with agencies having different service jurisdictions know how important this is.) The Allied Services Act requires common boundaries as a prerequisite to participation. The Governor, therefore, must establish uniform service areas across state agencies before any Allied Services Act benefits can accrue. Programs–such as Developmental Disabilities–having tried to tie together the resources of other programs for a particular target group when the boundaries of those other programs are tremendously varied, know how difficult these coordinative missions can be under such conditions.

3. **Goal Oriented Planning and Performance.**–Truly integrated processes require common goals which can incorporate the resources and missions of diverse providers. Allied Services has four antidependency goals as its focus. Preventing and reducing institutionalization is one of these key services goals. It also is a goal which if fulfilled leads to great cost-benefit returns. The Developmental Disabilities thrust is a significant contributor to this goal. The mentally retarded and other disabled groups constitute a large portion of the institutionalized population in most States. Inherent in the P.L. 91-517 mission is the earliest possible diagnosis and treatment of developmental disabilities. Consistent with the Allied Services goals, it is clear that the Developmental Disabilities program mission would be an essential area of emphasis.

4. **Funding Flexibility.**–Integration will not work without an ability to transfer and commingle complementary service resources. The Allied Services Act would allow up to 25% of one agency's funds to be shifted to any other related program purposes within the plan. We are not seeking to allow transfers from one program area to wholly different program purposes. The fund transfer provision can be approved only when the transferred dollars go to a related purpose. Therefore, in instances where four or five agencies are allocating a percentage of their resources to common activities and they wish to commingle their resources into a new more comprehensive, integrated package of services, under a lead agency auspice or a coalition program auspice, the fund transfer provision would enable this to happen. When funds are so transferred they do not lose their original identity in terms of subsequent agency budget requests. They simply are administered for a year under a different mechanism as agreed upon by the participating agencies. This funding feature would serve to give the coordinative charter of the Developmental Disabilities program the necessary leverage to move closer toward a fiscally integrated approach.

5. **Waiver Authority.**–Waiver authority is needed for two reasons. First, there are genuine instances whereby integrated services efforts are impeded by categorical statutory and regulatory constraints. Secondly, there are instances

whereby categorical constraints do not necessarily impede integration but are misrepresented as preventing real movement. In either case, the waiver provision of the Bill would work to alleviate constraints arguments—substantive and scapegoat alike—against integration.

6. Planning and Administrative Start Up Costs.—Finally, any agency or program participating in Allied Services stands to gain something for nothing. The bill would provide both the initial start-up planning and administrative costs associated with integration efforts. Frequently, even where there is a genuine interest in integration of staff, facilities, and information systems across agencies the realization of these efforts are stymied by the lack of unfettered overhead funds to support such efforts.

CONCLUSION

In these six important ways, the Allied Services Act would strengthen the ability of each human service agency to achieve its categorical ends. The Developmental Disabilities program would be one program which stands to benefit significantly within an Allied Services approach.

The Allied Services Act is not designed to supplant categorical service programs. It does not contain any new services money specifically for this reason. Rather the Allied Services Act is technical/means type of legislation which would add a new horizontal dimension to the existing services network in ways which are responsive to multiple needs and interdisciplinary solutions.

Most significant in our view . . that the Allied Services Act is designed to have teeth, through its various provisions, to bring about integrated and implementable approaches across a wide range of health, education and social service sectors within highly participatory state and local processes.

We hope you agree with our analysis that the Allied Services Act is imperative to the systematic improvement of the state of the human services art. We welcome your constructive comments about and criticism of the approach so that we can improve upon it prior to reintroduction in the next session of Congress.

APPENDIX

SUMMARY OF THE PROPOSED "ALLIED SERVICES ACT OF 1972"

The proposed "Allied Services Act of 1972" is intended to encourage states and localities to coordinate the provision of human services to individuals and families which will assist them in attaining the greatest feasible degree of personal independence and economic self-sufficiency, or which will prevent individuals and families from becoming increasingly dependent upon public and private programs for both financial support and personal care.

The Act would define various key terms. For instance, the term "human services" includes any services provided to achieve or maintain personal and economic independence. The "coordinated provision of services," means the provision of human services needed by individuals and families, in such a way as to (1) facilitate access to and use of the services, (2) improve the effectiveness of the services, and (3) use service resources more efficiently and with minimal duplication. These definitions help to restate the goals of the Act in clear terms—to lessen dependency through more effective service delivery.

Title I of the bill provides authority for the Secretary to make various types of project grants which may be needed by States and localities to plan and develop the capacity for the coordinated provision of services. There is also authority to provide technical assistance for planning or implementing a specific coordinated services program. Also, the Secretary is given authority to evaluate, directly or by grant or contract, the programs established under this Act. In addition to any salary and expense money he may wish to devote to evaluation, the Secretary may also use for this purpose amounts not in excess of 1% of the amounts appropriated to carry out the Act.

Title II describes the state and local allied services programs contemplated under this Act. Section 201(a) describes the steps which must be taken by the Governor as conditions precedent to the submission of a state allied services plan. First, he must divide the state into service areas (within which human services programs will be coordinated), after taking into consideration factors such as the distribution throughout the state of service needs and service resources, the boundaries of planning areas or areas for the delivery of individual service programs, and the location of units of general purpose local government. In the process of delineating service areas, he must inform units of general purpose local government of his plans and consider their comments and recommendations. The service areas should conform, to the extent found practicable by him, to any other areas within the state established for the planning or administration of human services programs. Second, he must determine, after consultation with the various public and private service agencies, whether a local allied services plan will be developed for any given service area. In the event that it is, then the Governor designates a local agency to take the lead in developing and assuring implementation of the local plan. Third, the Governor must designate a State agency which is under his direction and which will have responsibility for developing a state allied services plan incorporating local plans and implementing the state plan.

Section 201(b) provides that to be designated as described above, a local agency must be an office or agency of a unit of general purpose local government (or combination of such units) which has been chosen to act in this capacity by the chief elected official (or officials) of the unit (or units), or of a public or nonprofit private agency (which, for this purpose, is under the direction of the designated state agency), which can plan for and provide a broad range of human services, and must give assurance, satisfactory to the Governor, that it has the necessary ability to develop and carry out the local plan. The governor may designate a public or nonprofit agency, other than an office or agency chosen by a unit (or units) of general purpose local government, only if he finds that there is no such office or agency which has the capacity to carry out a local allied services plan.

The local allied services plan must be approved by the state agency and incorporated into the state plan before any of the forms of Federal assistance described below can accrue. The local plan must specify the agencies and organizations which have agreed to participate in the coordination effort, describe the service needs and resources within the service area, enumerate the programs to be included under the plan, and provide reasonable assurance that progress will be made in coordinating the provision of services. This assurance is to be provided by describing the specific functions and services to be coordinated, the benefits to individuals, and the administrative efficiencies to be achieved by the coordination.

It is the intent of this bill to have the active and continuous involvement of voluntary organizations, client groups, service consumers, and local social service providers in the planning and administrative processes of the program. Therefore, to ensure the program's responsiveness to the particular needs of each community, each plan must be accompanied by assurances that interested agencies, organizations, and individuals were afforded the opportunity to comment upon the plan prior to its submission to the state agency and will have an effective channel through which their views can be known with respect to the ongoing administration of the plan.

Section 202(a) prescribes the requirements applicable to a state allied services plan. An approvable plan must, (1) through a brief summary of the incorporated local plans, describe the current status of the coordinated provision of services, and the steps which will be taken to achieve a greater degree of human services coordination, (2) provide assurance that under each local plan services under the assistance titles of the Social Security Act will be coordinated with services under: any other three human services programs, any other HEW supported programs which the Secretary may specify, and any other such programs, regardless of whether they are receiving Federal support, which the state may desire to include, and (3) provide that the state agency will provide any other relevant information which the Secretary may request.

Subsection (b) directs that an opportunity to review and comment upon a state plan submitted for approval be afforded to the head of any Federal department or agency which is extending assistance to a program included within that plan.

Subsection (c) directs the Secretary to approve a state plan if he finds that: (1) the Governor has complied with the preliminary organizational requirements prescribed in section 201, (2) the plan meets all the specified requirements, and (3) the plan is designed to accomplish the purposes of the Act to achieve expansion of its coverage to other services and other service areas on a reasonable basis.

Subsection (d) provides certain penalties if the Secretary finds failure to comply substantially with the provisions of an approved state plan (or included local plan). He may in his discretion apply these penalties to the entire state plan or only those parts of the state or local plan or service areas affected by the noncompliance. In such instances, the subsection would provide: no Federal planning funds may be consolidated or intermingled with other such funds for human services planning, no Federal funds may be transferred among programs, no requirements may be waived, and no further payments or grants may be made (in the fiscal year for which the plan is approved) for so long as the failure to comply continues.

Section 203 describes the various types of Federal assistance which become available upon approval of a state allied services plan. Four types of assistance are available:

First, authority would be given both the Secretary and state and local governments with allied services plans to consolidate planning funds extended by the Department of Health, Education, and Welfare. Thus, the Secretary may make a single, consolidated grant of HEW funds available for planning for or under any program included in the approved State or local allied services plan. As a corollary, a state or a unit of general purpose local government, with an approved allied services plan, may use planning funds provided by the Department of Health, Education, and Welfare and available for any program included in this plan, for planning in connection with the provision of human services under any included program.

Second, a State or local agency with an approved plan may transfer up to 25% of the Federal assistance available for use under any HEW-assisted program included in the plan to be expended in carrying out any other included programs. Assistance transferred under this authority carries with it the matching rate established under the program for which it was originally appropriated, so that no incentive to transfer will be created merely by disparities in matching rates which exist among the included programs. The transfer authority does not apply, however, to the open-ended assistance programs under the Social Security Act, or to assistance provided under title I of the Elementary and Secondary Education Act (consistent with the Administration's special education revenue sharing bill).

Third, the Secretary is authorized to waive requirements of statewideness, single or specified state or local agency, or technical or administrative requirements imposed in connection with any included program which, at the Federal level, is administered by the Secretary and which the state or local agency certifies impedes implementation of its allied services plan. Thus, it would not affect the basic protections provided by the Civil Rights Act of 1964 or any other generally applicable legislation; nor would it apply to programs administered by other Federal departments or agencies.

Finally, the Secretary may make discretionary grants to meet costs of planning or preparing to carry out allied services plans, or to meet the administrative costs of coordination under a state or local plan, which cannot be met from other available funds. The state must indicate how it plans to allocate the funds applied for among the various designated local agencies with approved plans. These grants are not to be used to meet the non-Federal share requirements of any Federally-assisted program and may not be made to any state for more than two years except where the Secretary finds it is necessary to enable the state to carry out a significant expansion of its allied services plan.

Section 204 provides joint funding authority. It is almost identical to that contained in the juvenile delinquency law, the Economic Opportunity Act, the Older Americans Act, and the Law Enforcement Assistance Act. It goes somewhat further than those statutes in two respects: (1) it would permit joint funding of several grants made by the same agency, and (2) it would permit waiver of technical grant or contract requirements imposed by statute as well as by regulation.

Objectives of "Projects of National Significance"

George J. Bouthilet, Jr.

INTRODUCTION

This resource paper was prepared for the November 1972 National Conference of State Councils on Developmental Disabilities. The contents were presented and discussed at one of the workshops. It later was revised for application in the present volume.

PURPOSE – FOCUS & PRIORITIES

The Developmental Disabilities Services and Facilities Construction Amendments of 1970 became Public Law 91-517 on October 30, 1970. The Act authorizes grants for: (1) developing and implementing a comprehensive and continuing plan; (2) providing services to the developmentally disabled; (3) construction of facilities for the housing of services; (4) local planning, administration, or technical assistance; (5) training of specialized personnel for services and research; (6) developing or demonstrating new or improved techniques of service (7) construction of "university-affiliated facilities" for the interdisciplinary training of professional personnel; and (8) demonstration and training grants. Title I, Part C, of the Act includes: (1) formula grants to the States for planning, administration, services, and construction, and (2) set-aside grants (discretionary funds) for special projects of national significance. The latter, provided for under Section 132(e) of the Act, permits the Secretary to reserve up to 10 percent of the amount appropriated for the formula grant program for the support of special projects of national significance which will demonstrate new or improved techniques in the delivery of services, assist in meeting the special needs of the disadvantaged for services and facilities, and in carrying out the purposes of the Act (e.g., program planning, information, and evaluation).

The discretionary funds for special projects of national significance are being used to provide general support to all States through grants of national significance in the areas of planning, information, and evaluation. In addition to these basic areas, special projects of national significance may be funded in support of certain DD-related areas of high national priority (e.g., socially disadvantaged-handicapped child advocacy). Thus, the discretionary funds for special projects are for the purpose of providing the necessary assistance for effective implementation and efficient management of DD State plans and programs for a national framework. Because of limited funds for formula grants, and consequently, limited funds for special project grants, set-aside discretionary funds are used to support State leadership and program management functions, providing effective planning strategies, information and data systems, evaluation criteria for State plans and projects, technical assistance and consultation to the States, support for national conferences and workshops for State Councils, and other DD-related national priorities.

Demonstration of specific services, on the other hand, may be supported in part by (1) the State through use of its own formula grants for services, (2) any increased amount which is allocated through to the formula grant by reducing the total amount of set-aside funds withheld, and (3) utilization of other available project grant resources, with often larger amounts of discretionary funds, administered by the Division and numerous other related Federal programs serving the developmentally disabled population.

The effective utilization of limited DD set-aside national project funds dictates that the monies be used on a selected high priority and maximum impact basis. Thus, the provision of technical assistance to State Councils and the support of a national conference of State Councils received higher consideration than the demonstration of a specific service or expansion of an existing service in which other Federal grant funds are already available to assist in the specific endeavor. Of course, the above focus may be modified should larger sums of discretionary funds become available, permitting a wider range of funding in terms of kinds of projects. At the time of this writing, due to both the newness of the DD Act and limited appropriations, the focus must be on general and basic support for national impact through projects which will increase the effectiveness of State Councils and associated organizations and agencies.

Limitations on the number of Division staff and financial resources require the utilization of discretionary funds for special projects in order to serve the States more effectively from a Federal/national level. This approach plan permits the Division to use the best talent available throughout the nation and stretch the limited Federal dollars available so that all or most States will benefit from any single national project in the areas specified above. If each State were to expend its own funds for special projects as in this manner many more dollars and other resources would be utilized for national benefit.

STRATEGY – DISTRIBUTION OF FUNDS

The strategy specified for the use of these discretionary funds is to award grants for DD planning, information, and evaluation projects of national significance and impact to provide the necessary support for the effective implementation and efficient management of the DD program. Of the allowable amount of

10 percent which may be set-aside for special projects, it was determined by the Department to use 9 percent in FY 1972 and 1973; and of the allowable amount of one percent which may be set-aside for evaluation, it was decided by the Department to use the full 1 percent. Thus, a total of 10 percent has been set-aside in these two fiscal years. Applications for special projects are received, reviewed, and approved and funded directly by the Federal government (i.e., RSA/DDD with assistance from the DHEW regional offices). The National Advisory Council on Developmental Disabilities considers and reviews areas of support and advises the Secretary, DHEW, on selecting priority areas for special projects of national significance for the developmentally disabled. In collaboration, both the National Advisory Council and the Department arrive at an approved listing of areas for funding.

One-fourth of the 1 percent which is set-aside for evaluation projects is retained by the DHEW Office of the Secretary, Assistant Secretary for Planning and Evaluation, for Department-wide evaluation projects of high priority or special significance. These evaluation funds may be used for DD evaluation or DD-related evaluation projects. The funds are utilized at the discretion of the Secretary with consideration given to special needs of the DD program (e.g. use of the evaluation funds for a project to survey the number and kinds of projects supported with State administered formula grant funds).

Evaluation plus five other special areas has been designated as having high priority for support under the initial strategy for special projects of national significance. Limited resources prevent consideration of additional areas at this time, although new areas will be identified as additional resources are made available. In addition to evaluation, the current priority areas include the following: (1) advocacy, (2) technical assistance, (3) national data base, (4) national conference of State planning and advisory councils, and (5) deinstitutionalization.

MANAGEMENT – PROPOSALS, APPLICATIONS AND GRANTS

Except as may be indicated otherwise in information statements which are issued from time to time, the following applies to the processing of proposals and applications and the submission of reports. The originating organization forwards proposals and applications for project grants and reports on special projects of national significance for developmental disabilities directly to the Director, Division of Developmental Disabilities, Rehabilitation Services Administration, Social and Rehabilitation Service, U.S. Department of Health, Education, and Welfare, Washington, D.C. 20201. Subsequently, copies of the above documents are forwarded by the central office to all regional offices of the Department of HEW for information, review, and comment.

The developmental disabilities program consultant in the region from which the proposal or application originates, prepares and provides additional relevant and specific information and data on the appropriateness and adequacy of the organization submitting the document. Regional office consultants in all regions, especially one who has technical competence in the special subject area of the document, provides additional information and data on the content of the document (e.g., objectives, methodology, staffing, budget). Special problems will be pursued by the designated central office staff, with assistance from the regional office staff, through review and discussion with the appropriate person(s) in the organization(s) submitting the document(s). Monitoring of all projects is a collaborative endeavor between the central and regional offices. Evaluation of the project is the responsibility of the designated project officer.

Proposals and applications received which do not fall in one of the joint National Advisory Council and Department of Health, Education, and Welfare (DHEW) designated priority areas for funding will be returned with an explanation. A letter is sent to the originating organization informing them of current priority areas for funding of special projects of national significance, indicating the present status of their own proposal or application in relationship to the approved priority areas, providing clarification on specific items as may be needed to assure an understanding of the origin of priorities and other relevant procedural matters.

Applications which fall in one of the joint priority areas for grant support are considered for review with other applications falling within the same priority area. Applicants are informed of the results of the review and subsequent recommendations made. Organization resources, staff experience, specification of project objectives and methodology, design for evaluation, and cost-output (product) are among the criteria considered in competitive review of an application for funding.

Initially, all proposals and applications are screened for (1) whether or not they fall in one of the designated joint priority areas, and (2) whether or not they are of national significance. Generally, a project which touches on all or at least a significant number of States and territories simultaneously is considered national in scope (e.g., the project grant for a national conference of State Councils). In contrast, a proposal for a project which is conducted in a single State as a possible model for other States, may or may not be considered "national" (e.g., "model project for a counseling service"). On the other hand, a nationwide geographical distribution of a small number of closely associated individual projects falling within a single priority area may form a national network of related projects of national significance (e.g., 10 State projects for preparing "deinstitutionalization" plans, which are located on the basis of one project in each of the 10 DHEW regions, might provide national geographical distribution of projects supporting a priority area).

Specific priority areas will change from time-to-time as priority projects are being funded. It is not possible to distribute a list of current priority areas to *all* potentially interested organizations in the nation. However, the National Advisory Council, State Planning and Advisory Councils, and the Federal central and regional offices of DHEW are informed as to the current and proposed priority areas, and serve as information points.

Information statements and guidelines are prepared and made available by the Director, Division of Developmental Disabilities. These are issued from time-to-time depending upon changes in priorities, grants management procedures, and other matters relevant to administration of special projects of national significance. A general information statement on the program was issued in the early part of 1971 following passage of the Developmental Disabilties Act in late

1970. This statement included a section on special projects of national significance. Additional information statements and guidelines are prepared for distribution as needed to ensure orderly management of the grants and to respond to special priority areas (e.g., State planning grants for "deinstitutionalization").

DESCRIPTION OF AREAS AND PROJECTS

The special projects of national significance may be divided into two major categories: (1) planning and information and (2) evaluation. The order of presentation does not reflect order of importance. The initial five priority areas for special projects are in the category of planning and information and represent strategy jointly reviewed and approved by the National Advisory Council (NAC) and by DHEW through the Division of Developmental Disabilities, Rehabilitation Services Administration (DDD/RSA).

The sixth area includes two evaluation projects; these projects are summarized following the above five areas. The evaluation projects are also reviewed and approved in a collaborative manner between the NAC and DHEW through DDD/RSA. However, the NAC has a special responsibility for the area of evaluation as specified in the DD Act and, as a consequence, an Evaluation Committee has been designated to work with the planning and evaluation staff of DHEW. A DD Evaluation Plan, now in preparation, constitutes another collaborative endeavor between the two organizations. All project areas are considered in terms of national needs and priorities.

The State planning and advisory councils may participate in setting priorities for special projects of national significance through either the NAC and/or the DDD/RSA. A review of the priorities listed in the State plans for DD, a State councils "needs assessment" survey, and State/Federal regional office communications, all offer opportunities for State input into establishing national needs and priorities. Other mechanisms may be explored and tested in order to promote an effective approach to priority setting for these projects.

Implementation of the strategy for using developmental disability discretionary funds for special projects of national significance are described below. Some areas may include more than one project. The priority areas, project titles, organizations, goals and objectives, and amounts of each grant are given.

I. Advocacy Projects

A. Child Advocacy: $150,000

DDD/RSA has joined with BEH and NIMH in comingling funds to support five national priority child advocacy projects. The RSA contribution of $150,000 is matched in similar amounts from each of the other agencies.

The projects, approved by an independent review committee, meet our DDD/RSA needs and are in concert with DDD/RSA OPS objectives and long-range goals.

The projects approved are:

Projects	*Award Recommendation*
1. NARC	$ 66,000
2. Peabody College	101,000
3. Kentucky Commission on Children	106,000
4. National Easter Seal Society	106,000
5. U.C.P.A.	101,000

Total new starts FY 1972 – $480,000

1. National Association for Retarded Children, Inc. – Arlington, Texas.

The NARC project aims at catalyzing the development of a nationwide volunteer child advocacy program. Local and State Associations for Retarded Children will serve as the implementation agencies. Primary objectives of the project include: (1) developing written and audiovisual materials to elicit understanding of, and commitment to, the citizen advocacy model; (2) developing a standardized training program to enable the establishment of Child Advocacy Boards and local and state advocacy offices, the identification of mentally retarded children in need of advocacy services, and the training of citizen volunteers to serve as advocates for mentally retarded children; and (3) providing direct program consultation to assist NARC member units in establishing model programs. It is anticipated that the project will have a significant positive impact upon the delivery of needed services and programs to mentally retarded children, as well as upon the overall environment within which these programs and services are provided. The advocacy services developed will provide a concrete national prototype which may be applied in efforts to obtain improved services for other handicapped and/or disadvantaged children and youth.

2. Peabody College – Nashville, Tennessee

This Child Advocacy Research and Demonstration Program proposed four General Advocates in four rural counties, with roles modeled after that of County Agricultural Agents. They will seek to identify unfilled expressive and instrumental needs of children in the counties and to procure the satisfaction of those needs through increased knowledge and understanding of child development by parents, families, community clubs and organizations and three sets of systems described in the proposal as the Key Integrating Systems of Society, the In Trouble Systems and the Institutional Care Endeavors. The County Agents will seek to promote understanding of the findings of research in education and child development by the foregoing agencies in a manner similar to that used by County Agricultural Agents. These efforts will be augmented by developing Individual Citizen Advocates for individual child proteges where needed to fill unmet expressive and instrumental needs of such children. Data and experiences will be procured and evaluated relating to the program and its objectives with a view to replicating the program elsewhere.

3. The Kentucky Commission on Children & Youth – Frankfort, Kentucky

The Kentucky Commission on Children and Youth proposed to conduct research and demonstrate the feasibility of establishing state and regional offices of Advocacy for Exceptional Children and Youth. It is proposed that the State and regional offices would develop mechanisms to insure the attainment of the following goals and objectives: (1) formulation and advocacy of special legislation vital to the needs of exceptional children; (2) serving as an appeals agency or ombudsman in dealing with the grievances of exceptional children and their families; (3) serving as a watchdog or guardian of the rights of exceptional children; (4) providing educational information and statistical data to state officials, the legislature and the general public concerning the needs and problems of exceptional children; (5) developing and establishing a unified policy framework within which statewide goals for exceptional children are formulated, service priorities established, existing programs kept in balance, and new programs developed; (6) insuring that coordination involves the management of human and fiscal resources to avoid waste, duplication, conflicting program objectives, and gaps in existing services; and (7) evaluating agency programs to assure maximum effectiveness for quality control and accountability.

4. *The National Easter Seal Society for Crippled Children and Adults – Chicago, Illinois*

This project proposed to establish and perfect a model of advocacy for physically handicapped children in Massachusetts that can be replicated by any affiliate of the National Easter Seal Society for Crippled Children and Adults. Through the establishment of a Child Advocacy Association and Board, it is hoped to bring together parents and interested persons from schools, public and private agencies and the community to achieve change in legislation, policies, practices, and attitudes which prevent physically handicapped children from achieving basic rights related to home, community, schooling, medical care and legal rights. It is also hoped to find physically handicapped children who are deprived of these rights and act on their behalf on an individual basis. The staff will consist of a Project Director, Child Advocates and consultants in research education and child development, law, medicine, mental health and sociology. Expected benefits to child, family and community agencies and schools include the removal of barriers to the improvement and extension of their services.

5. *United Cerebral Palsy Association*

United Cerebral Palsy Associations, Inc., Proposed to establish three models of advocacy for children with developmental disabilities and their families (in New York State; Milwaukee, Wisconsin; San Mateo and Santa Clara Counties, California). These three models will be coordinated by the national organization. The purpose of the project is to provide an advocacy program to assist children with developmental disabilities and their families to obtain needed services and to make the best use of available resources. In addition, data of various kinds in regards to service needs of children with developmental disabilities will be collected and collated at the State and local levels and organized by the national organization. These data will be used by the State, local and national organizations to develop necessary legislation at all levels of government. This will make it imperative for the various organizations to work with legislative bodies and governmental agencies. It will also be essential to work with consumers and consumer groups to urge their participation in community organization, planning and legislative processes. It will also be essential that all organizations work toward implementing already existing official programs. This will be accomplished by employing four qualified persons, one in the National Office and one in each of the three affiliates. The three local advocates in this project will have the responsibility of developing the three models. The four advocates will organize necessary National, State and Local Advocacy Advisory Councils to give impetus to the program, provide guidance to the advocates and evaluate the functioning and accomplishments of the models. It is proposed that local financial participation will increase beginning in the third year so that the models can be tested in other areas of the country during the five year period. State and local affiliates have agreed to participate financially in this manner and to continue the program after the five year project period has been completed.

DDD/RSA has made arrangements for participation in the monitoring of the five child advocacy projects funded this year by the Bureau of Education for the Handicapped, the National Institute of Mental Health, and the Rehabilitation Services Administration.

B. Legal Advocacy

The Council for the Retarded of St. Joseph County, South Bend, Indiana, and Notre Dame University

This is a joint project involving DDD/RSA and BEH/OE. It seeks to establish a national clearinghouse for law information, to provide *"Amicus Curae"* for the courts and to provide technical assistance in legal areas as it pertains to developmental disabilities.

The proposed legal advocacy will include the following:

1. Maintenance of an up-to-date reference system for all national state legislation pertinent to the welfare or potential welfare of the developmentally disabled.
2. Maintenance of an up-to-date reference system for all national, state and local legal action pertinent to the welfare or potential welfare of the developmentally disabled.
3. Provision of an electronic retrieval system for all data recorded to access the system for short term feedback to any legitimate requesting party.
4. To research questionable issues, pertinent to the legal rights of developmentally disabled persons, and to provide empirically based position papers on such issues.
5. Development and maintenance of communication for specific lines of input and feedback from local and state Bar Associations.
6. Development of model legislation for laws dealing with the rights of developmentally disabled persons which reflect a national "quality of life."
7. Development of model pleading and briefs relating to the institution of legal proceedings to secure the rights of developmentally disabled for concerned organizations or practicing attorneys.
8. Serving as Amicus Curae in court cases involving the rights of developmentally disabled persons, to compile a roster of expert witnesses and to provide technical assistance in coordinating expert testimony with existing and proposed litigation.
9. Assisting practicing attorneys in preparing briefs or a legal course of action for specific law suits.
10. Utilizing law school students and students in the behavioral sciences to research the law and obtain appropriate empirical data regarding specific relevant issues.

11. Developing a clinical education seminar dealing with the psychological, sociological and legal aspects of the developmentally disabled, and the specific concerns for equal opportunities thereof, to be offered to Notre Dame Law School students.

12. Developing short seminars or workshops dealing with the rights of disabled persons for practicing judges, attorneys and law enforcement agencies.

13. Developing a series of short term clinical education workshops dealing with disabling conditions and the law, to be offered to any law school in the nation.

14. Developing a legal advocacy model and to assist in disseminating and implementing the model in any law school or other appropriate agency at minimal cost.

15. Developing a legal advocacy education program for the handicapped and their families to assist them in obtaining appropriate services through a knowledge of the social systems in which such services exist.

First year Federal funding of this project is $168,000, RSA and BEH will each provide $84,500.

II. Technical Assistance Projects

A. *Technical Assistance to State Councils for the Developmentally Disabled.*

The University of North Carolina proposes to establish a Technical Assistance and Consultation System.

Goal: The Technical Assistance and Consultation System is to develop a strategy and organization and deliver technical assistance and consultation to the state and territorial developmental disabilities councils, assisting them in their task, especially in program planning and evaluation, program management, information and data dissemination, and developmental disabilities education and training activities.

Objectives: The Technical Assistance and Consultation System is to develop a small central staff at the University of North Carolina, Chapel Hill and ten regional technical assistance teams which will draw upon available technical assistance from a "talent bank" consisting of the best available personnel in the relevant technical assistance areas who can be brought together to assist in this national scope technical assistance program.

It is to develop and conduct a needs assessment of the developmental disabilities councils in order to begin individualized programs of technical assistance and consultation to each of the developmental disabilities councils.

Strategy: The organization of the Technical Assistance and Consultation System is to consist of four basic elements: (1) *a central staff,* (2) *an advisory group,* (3) *a talent bank* and (4) *ten regional technical assistance teams.*

1. The *central staff* will include professional specialists in the area of developmental disabilities, program planning and evaluation, communications and information dissemination, and research utilization. Central staff will be assisted by a program coordinator and two research assistants.

2. A small *advisory group* (five members) will be drawn together to assist the central staff in its planning and development. This advisory group will meet twice annually with the project director and his staff and other relevant administrators, including representatives of the Division of Developmental Disabilities. The purpose of the advisory group is to provide top flight assistance, perspective, stimulation, evaluation and overall surveillance of the System's development and operations.

3. A three-person *regional technical assistance team* will be developed in each of the HEW regions. Each team will consist of two specialists, one from program planning and evaluation, and the other from developmental disabilities. The third will be a designated staff member in the developmental disabilities section of the appropriate regional HEW office. This combination of regional office staff and specially trained technical assistance personnel in developmental disabilities and program planning and evaluation will constitute the nucleus of activity in each region for the needs assessment, pilot technical assistance delivery and eventual full scale technical assistance operations of the Technical Assistance and Consultation System.

4. The *Talent Bank:* The regional technical assistance teams will require a pool of technical assistance talent from which to draw in order to complete the needs assessment and technical assistance activities. In order to provide an economical but available talent bank made up of the most competent planning, evaluation, developmental disabilities programming, communications, and staff development personnel, a *talent bank* will be put together by the central office that will consist of approximately 50 to 75 professionals from all over the country who will agree to make themselves available for from 3 to 5 days each year and who will be deployed on request from regional technical assistance teams as their own needs develop and as service activity needs dictate.

The total FY 1973 budget amount is $364,699 for the first 9 months of the project, beginning October 1, 1972. The total project period runs from October 1, 1972 through June 30, 1975 for a total project amount of $1,201,587.

B. Technical Assistance on Public Policy (TAPP) for the Developmentally Disabled.

A proposal to study and recommend approaches of providing planning and public policy technical assistance methodologies is being reviewed. As recommended by the Bureau of Developmental Disabilities, Executive Office for Administration and Finance, Commonwealth of Massachusetts, the proposal suggests that a university based center with a national reputation and expertise in government, public administration, and public policy undertake the development of a Technical Assistance Unit in Public Policy and Planning for the Developmentally Disabled. This unit would be required to develop specific products for the Division of Developmental Disabilities, RSA, and the National Advisory Council for Developmental Disabilities.

Through a National Planning and Policy Developmental Task Force comprised of representatives from DHEW and other Federal Departments involved in programs for the developmentally disabled, and the National Advisory Council and State Planning and Advisory Councils' representatives to be staffed by the

TAPP unit and RSA staff, policy position papers are to be generated with respect to overcoming gaps and deficiencies in existing Federal legislation. Once determined, gaps and deficiencies in Federal law, regulations, and guidelines would serve as baseline information for the National Planning and Policy Development Task Force. Developing solutions and recommending policy changes to achieve greater inclusion of the developmentally disabled in the Federal-State resource allocation streams would require the development of options by the TAPP staff.

The products envisioned here are specific policy reports to the National Advisory Council for Developmental Disabilities on the quality, extent, and scope of all Federal programs with high relevancy to the developmentally disabled.

To undertake such an endeavor it is proposed that the selected "center" operate under a five-year project whereby all generated products are reviewed as implementation materials for the National Advisory Council for Developmental Disabilities and the Division of Developmental Disabilities.

No application has been received and no project has been funded as of November 1, 1972. Approximately $500,000 was set-aside for technical assistance projects in the initial years for special projects of national significance. This amount may be modified pending an application for a project grant in the above area.

III. National Information and Data Base for the Developmentally Disabled.[1]

The Pacific State Hospital, Pomona, California, plans to identify developmentally disabled individuals receiving services and establish a model data system for tracking developmentally disabled individuals through a continuum of services in various geographical areas of the country. Also, an evaluation will be made of the type and range of services used including living arrangements, in terms of subsequent changes in the individual's developmental status. Finally, an analysis will be made of the relative cost for living arrangements and services received which will also be related to individual developmental outcome.

The proposed project has a number of specific aims under each of its four main objectives:

(1) To identify developmentally disabled individuals receiving services in selected geographical areas of the United States.

(a) To assess their developmental status in terms of ambulation, toileting, arm-hand use, and other characteristics.

(b) To determine their living arrangements, whether at home, in a traditional residential institution, or in some type of community residential setting.

(c) To ascertain what short-term and extended services they receive.

(2) To track these same individuals through a continuum of services over a period of time.

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[1] **This project is described in more detail in a separate paper by Dr. Richard Eyman. The objective is presented here for purpose of having a complete paper on all DD special projects assembled in one document.**

(a) To assess changes in their developmental status.
(b) To determine changes in their living arrangements.
(c) To ascertain what changes take place in the services they receive.

(3) To correlate changes in the developmental status of these individuals with their living arrangements and the services they receive.

(a) To evaluate the effectiveness of different living arrangements and services in producing changes in their developmental status.

(b) To devise and implement procedures for the collection of such data from a large number and variety of sources and for their processing, evaluation, and reporting from a single center.

This study is an attempt to fill the void that exists in terms of information about services and those individuals receiving them. If the study's objectives are met, the result will be the development of model data systems which identify the supply and demand of services to the developmentally disabled, as well as their cost and efficacy.

The project period runs from 9/1/72 through 8/31/75 for a total amount of $463,195. The FY 1973 budget amount is $185,552.

IV. National Conference of State Councils.

The Council for Exceptional Children conducted a national conference of State planning and advisory councils on services and facilities for the developmentally disabled on November 16, 17, 18, 1972, in Washington, D.C. (This paper was prepared for the conference.)

The purposes of this conference were as follows:

1. To encourage fuller understanding and effective implementation of the Developmental Disabilities Act of 1970 by those principally charged with its execution.

2. To provide technical information relative to the functions of planning and evaluation of services for the Developmentally Disabled.

3. To develop and extend communication between the National Advisory Council on Services and Facilities for the Developmentally Disabled and the respective State Planning and Advisory Councils.

4. To provide a forum for considering the issues related to extension and modification of the Act.

Participants included members of State Councils (including territories), members of planning staffs of State Councils, representatives of State Administrative Agencies, representatives of University-Affiliated Facilities, National Advisory Council members, RSA Regional Office staff related to Developmental Disabilities, and representatives of national organizations concerned with Developmental Disabilities.

There were five distinct workshop time periods, three having 18 simultaneous workshops, one having 17, and one having 10. There were a total of 38 different topics, with selected ones being repeated in different time periods. Examples of topics are as follows: (a) Topic 1—"Allied Services Bill"; (b) Topic 3—"Data Gathering and Analysis"; (c) Topic 9—"Priority Setting in the Planning Process."

The project period runs from June 30, 1972 through June 30, 1973 for a total amount of $138,090.

V. Community Alternatives and Institutional Reform (CAIR) for the Developmentally Disabled (Deinstitutionalization).

The failure of institutionalization as a public policy has been acknowledged for over a decade, the President's panel in 1972 questions the efficiency of multi-purpose residential facilities of more than 500 residents. More recently a number of institutions have been cited in the Federal Courts as unconstitutional facilities violating the residents' rights to due process and equal protection of the laws. President Nixon has provided additional impetus for de-institutionalization by establishing a national goal of reducing the number of institutionalized mentally retarded persons by one third. The National Advisory Council and the Department of Health, Education, and Welfare are supportive of this Presidential initiative.

Developmental disabilities special project grants, including grants from other related Federal programs, are to be awarded to assist the States to improve and expand supportive community services, improve the quality of residential care (institutional reform), and provide community based alternatives to institutional care for the developmentally disabled, including:

A. Planning, developing, and implementing an SRS interagency role of community alternatives and institutional reform (CAIR) for the developmentally disabled;

B. Assisting all States to prepare statewide deinstitutionalization plans.

C. Enabling 10 States to implement statewide programs for community care and deinstitutionalization which will:

(1) Stabilize admissions to public institutions for the mentally retarded;

(2) Screen DD persons in institutions or individuals at risk of institutionalization in terms of potential for community placement and need for community services.

(3) Place developmentally disabled individuals in community based settings.

(4) Provide developmentally disabled individuals at risk with alternative supportive services in the community.

Upon the development of an SRS plan and criteria, selected States will be assisted in planning, developing and implementing prototype programs to demonstrate measurable impact in turning from institutionalization to community alternatives. Alternative care options and priority service areas will be determined by the needs of each State and will most likely differ from State to State.

At the time of the writing of this paper, approximately $2,000,000 has been set-aside out of DDD funds for special projects to support the above objective. No projects have been funded as of November 1, 1972. The exact amount of funds to be comingled with other Federal programs in support of this objective is yet to be determined. Also, further specification in use of these funds for this area must be determined.

VI. Evaluation Projects.

Evaluation projects may be supported with set-aside funds from the DD Act, Title I, Part C, formula grant program and Part B, university-affiliated facilities program. One percent of the program appropriation may be utilized for purposes of evaluation of the program in order to assess its accomplishments and effectiveness.

The National Advisory Council for Developmental Disabilities has two responsibilities as described in the DD Act, one of which is to study, and evaluate programs for the developmentally disabled. The National Advisory Council has established a DD Evaluation Committee with three members. The Evaluation Committee met with the Planning and Evaluation Branch staff of the Division of Developmental Disabilities, Rehabilitation Services Administration, on two occasions to date. On June 14, 1972, a preliminary consultation meeting was held in which DD evaluation proposals, applications, and projects were reviewed in order to establish an effective working relationship between the Council and the Federal program. On August 11, 1972, the first official meeting of the NAC Evaluation Committee and the DDD Evaluation Branch took place. At this meeting a special focus was given to developing an outline for a long-range DD Evaluation Plan. The initial rough draft of the DD Evaluation Plan has been completed and distributed for review and comment by NAC and DDD staff. Upon revision, the DD Evaluation Plan will be shared with the total NAC membership and forwarded up the organization line for further review and comment. The Evaluation Plan has a national focus, with a State and local framework for assessing program impact and strategy. The Evaluation Plan will provide a guide for evaluation of the program, setting priorities for evaluation projects to be undertaken. Stimulation and funding of evaluation projects will follow the Evaluation Plan.

The two evaluation projects which are currently being supported with DD funds include a project a Florida State University and one at Brandeis University.

1. Development of Evaluation Criteria to Assess State Plans for the Developmentally Disabled.

Florida State University was awarded a 2½ year grant for a project to develop a framework for assessing State plans in the area of developmental disabilities. In accomplishing this task, the project is concerned with establishing the factors which are important in determining the effectiveness of State plans, which includes setting down criteria by which State plans can be evaluated, determining what information and data is needed to know if these criteria are being met, as well as testing and modifying the evaluation system once it has been formed.

The project is in its second year of operation. The efforts in the first year have centered essentially on developing the background information necessary for establishing evaluation criteria. It includes a review and analysis of all State plans for the developmentally disabled, and an in-depth study of a small sample of States to monitor planning and program changes.

The project will develop criteria for assessing State plans through a study of the following: (1) the relationship of the designated 16 services to the other nine State plans as listed in the legislation from the program and financial aspects; (2) the analysis of the significance of variations in selected State usage of DD funds for planning, administration, services, and construction; (3) the relationship of proposed and existing projects to the overall plan; (4) the mechanisms for compliance with the human rights regulations; (5) the accessibility to facilities and services especially with respect to poverty areas; (6) the analysis of "statement of need" priorities, and objectives, in relationship to resources; (7) the tie-in of university-affiliated facilities and programs for the developmentally disabled; (8) the tie-in of programs not included in the DD Act but directly administered by the Division of Developmentally Disabled, e.g., V.R. Section 4(a)(1)–"Rehabilitation Services for the Mentally Retarded"; and (9) other factors identified in the review of State plans and in the survey of selected States.

An interview schedule has been developed and utilized for reviewing and analyzing the selected States in the survey in order to obtain more in-depth information and data on planning and programming. The selection of the States themselves was based upon carefully considered criteria, including the nature and scope of the State planning and advisory councils and the State programs in order to ensure heterogeneity. The States selected participate on a voluntary basis following consideration of the State councils. The evaluation criteria for assessing State plans will be shared with all States and territories participating in the formula grant program. It is recognized by the evaluation project staff that each State is unique and will produce a different State plan, taking into consideration the State's own needs, resources, and problems which result in different objectives and priorities.

The project period runs from June 14, 1971 through January 31, 1974, for a total amount of $232,000. The project is in its second year of operation, with a grant award of $89,777.

2. *Evaluation of the Process of Periodic Review of the Developmentally Disabled.*

Brandeis University, Florence Heller School for Advanced Studies in Social Welfare, plans to evaluate the results by the newly enacted legislation in Massachusetts requiring an annual review of persons in State Schools for the Mentally Retarded. Because of the leading nature of this legislation, the results of this evaluation will have national significance in determining the course of action in other States.

The evaluation study will consist of three phases, each requiring roughly a calendar year to complete. These are:

Phase I will provide for a) a systematic and in-depth testing and evaluation of a stratified random sample of all persons identified as having one or more developmental disabilities, and b) a preliminary search of statutes, regulations and the available legal literature pertaining to periodic reviews of institutionalized and non-institutionalized populations.

Phase II will be an evaluation of the legally required review process with respect to which types of developmentally disabled residents of State institutions for the retarded secure in the process of review, a change in treatment, or placement in any of the available alternative programs within or outside the institution.

Phase III will consist of a) a follow-up evaluation of subjects using Phase I measures to determine changes in the resident's economic, social, environmental, health, educational and legal status by employing social, psychological and biomedical standards and measures, associated with review and/or treatment interventions, and b) preparation of a model law concerning annual reviews of residents in institutions for developmentally disabled persons. The justification for the above program lies primarily in the weakness of available information regarding such persons with developmental disabilities and their parents or legal guardians and its scattered, inconsistent, and generally inaccessible character.

The project period runs from July 1, 1971, through June 30, 1974, for a total amount of $342,285. The project is in its second year of operation, with a grant award of $92,262, $74,653 of this amount is from the developmental disabilities program and the remainder is from the vocational rehabilitation program.

3. Evaluation of University-Affiliated Facilities.

Evaluation projects may be supported with funds from Part B of the DD Act, university-affiliated facilities program. Again, 1 percent of the budget may be used for evaluation purposes. At this time, no UAF evaluation project is being funded with these monies. The amount of funds available is small (i.e., $42,250). Of this amount 25 percent is deducted by the Office of the Secretary for use by the Assistant Secretary for Planning and Evaluation, which leaves the Division with about $31,875 for such purpose.

Appendix A

FISCAL STATUS REPORT – NOVEMBER 1972

I. Funds Reserved for Projects of National Significance (9% of Title I, Part C, Appropriations)		
FY 72		
9% of appropriation of Title I, Part C funds can be obligated until June 30, 1974		$1,954,350
Obligated as of January 1, 1973		-234,500
Legal Advocacy Center at Notre Dame	84,500	
Joint Advocacy Projects with BEH-NIMH	150,000	
Unobligated FY 72 funds		$1,719,850
FY 73		
9% appropriation for Title I, Part C funds can be obligated until June 30, 1973. Regulations require funds to be obligated by April 1, 1973 or returned to the States.		$1,954,350

Obligated as of January 1, 1973		-661,834
Technical Assistance to State Councils	364,699	
National Conference of State Councils	130,114	
National Data Base	167,021	
Expected continuations and new projects		-525,000
Child Advocacy (BEH-NIMH)	175,000	
Legal Advocacy	100,000	
Technical Assistance for Policy & Planning	250,000	
Unobligated FY 73 funds		$ 767,516
Total Unobligated funds (FY 72, FY 73 Projects of National Significance)		$2,487,366

II. Funds Reserved for Evaluation (1% of Title I, Part C, Appropriations)

FY 72		$217,150
Obligations		-217,150
State Plans Analysis/Criteria	89,777	
Periodic Review Process	74,653	
Office of the Secretary (¼ of 1%)	52,720	
Unobligated funds		000
FY 73		$217,150
Expected continuations to be obligated		-217,150
State Plans Analysis/Criteria	89,777	
Periodic Review Process	74,653	
Office of the Secretary (¼ of 1%)	52,720	
Unobligated funds		000

Development and Recognition Of Human Rights for the Developmentally Disabled

Stanley Herr

On December 27, 1971, the General Assembly of the United Nations adopted a resolution entitled "Declaration of the Rights of the Mentally Retarded." Notwithstanding its endorsement by an overwhelming majority of nations, the resolution, as well as the substance of the humane and legal principles set forth therein, is more commonly disregarded than observed. In many respects, the time is especially appropriate to examine the steps which can be taken to implement and enforce those rights. Of particular importance is its recognition that the retarded person has a "right to proper medical care and physical therapy and to such education, training, rehabilitation and guidance as will enable him to develop his ability and maximum potential."

Developmentally disabled citizens, historically among the most silent of Americans, are now demanding their right to the services of the public sector. Through litigation and legislative advocacy, their attorneys and advocate organizations have served notice on the agencies of government that access to public education and related developmental services is a matter of right and not charity. For the 275,000 children and adults in this country who live in facilities for the mentally retarded, the focus of advocacy is the "institutionalization, dehumanization and neglect to which we have so long relegated many of our mentally retarded under the guise of care and concern."[1] And for the nearly one million handicapped children either excluded from public education or otherwise denied a free and suitable education,[2] recent federal court decisions such as *Mills* v. *Board of Education*[3] are encouragingly ending such practices.

THE CHILDREN OF *MILLS*

Who are the school-excluded children? They are the "slow" Gregorys, suspected of being mentally retarded, indefinitely suspended for alleged disciplinary infractions, whose parent is told to wait for a call from the principal when "our school has a small class for your child." And they are the seizure-stricken

Michaels who are shunted from one custodial institution to another while the public school system refuses to create special educational programs to serve them. And they are the Janices who are so profoundly retarded that public schools deny them admission to suitable learning programs (or to any program), leaving harassed parents in the cruel dilemma of either institutionalizing their child or bearing the burdens of 24 hours a day, 7 days a week care. When such parents are unaided by community agencies or lack funds to obtain private care, the state imposes upon both child and parent a virtual house arrest. Often the only remaining "option" left to these parents is commitment of their child to a public institution. Yet, in too many of these institutions–sorely overcrowded, starved for funds and staff, improperly managed–living conditions are barely conducive to physical survival, let alone habilitation.

A visit to custodial institutions for the retarded reveals a harsh array of sights, sounds and smells. Many of the abuses have been chronicled in the *Wyatt v. Stickney* case.[4] During discovery proceedings at the Partlow State School, for example, I saw a teenage boy in a strip-cell, mute and naked, who had been kept in nearly continuous isolation for the preceding five years because behavior modification programs were unavailable. At Partlow, I spoke to a middle-aged man, dressed in overalls, who quietly, but clearly described to me a life of nearly forty years of peonage in that institution's laundries, dining halls, and cotton fields. Yet, in recounting his personal history, he revealed enough intelligence and evident capacity for self sufficiency to raise questions as to the "rationale" behind his confinement in an institution for the retarded.

Perhaps no sight is more cruel than the unnecessary infliction of pain upon a young child. In the basement of one of Partlow's dormitories, there was an "experimental" program in which untrained attendants administered electric jolts from cattle prods to the misbehaving. The faces of the children confined to that ward will not be forgotten, nor the daily inhumanity and anguish of their confinement.

THE DEVELOPMENTALLY DISABLED PERSON'S DAY IN COURT

On August 1, 1972, the United States District Court for the District of Columbia held that the handicapped child has constitutional rights to a specialized publicly-supported education:

> The District of Columbia shall provide to each child of school age a free and suitable publicly-supported education regardless of the degree of the child's mental, physical or emotional disability or impairment.[5]

The Court expressly enjoined the practice of excluding school-age children from regular public school assignments without providing them, at public expense, a suitable immediate educational alternative. It further declared that each child is constitutionally entitled to a hearing prior to his assignment to any such alternative program and to periodic reviews of the appropriateness of that assignment. The *Mills* case is thus the first declaration of the constitutional right of *all* school-age children to public education.

Four months earlier another federal court, in *Wyatt v. Stickney*, had held that an involuntary committed mentally retarded person is constitutionally entitled to adequate habilitation.[6] In examining conditions at Partlow State School, Alabama's major institution for the retarded, the court confronted a "human warehouse" which denied to its 2,300 inmates even the most elementary care and training. Citing overcrowding, subcustodial staffing, and numerous "atrocities,"[7] the Court found a continuing violation of plaintiffs' rights and ordered the prompt implementation of minimum professional and medical standards. In enunciating the right to habilitation, the degree in *Wyatt* recognized the constitutional obligation of public authorities to provide adequate care, treatment and training to the institutionalized retarded. Other recent federal court decisions in Pennsylvania[8] and Massachusetts[9] suggest that such judicial scrutiny of public services for retarded and other handicapped persons may become increasingly common.

An estimated 6 million Americans are classified as mentally retarded.[10] Sixteen million others have mental, physical or behavioral impairments sufficiently disabling as to require special educational and therapeutic services.[11] Yet, across the nation millions of retarded or otherwise handicapped children continue to be denied admission to public schools or to be consigned to inappropriate services through misclassification or the absence of educational alternatives.

Institutions still exist where a person, solely because of mental deficiency, can be denied freedom, confined to unspeakably overcrowded living quarters, and required to work without pay in virtual slavery.[12] Incarcerating the retarded in institutions like Alabama's Partlow or New York's Willowbrook makes a sham of the benevolent and humane considerations said to justify the state's interest in the retarded. By recognized standards, these institutions barely provide adequate custodial safekeeping for their charges, let alone habilitation. Notwithstanding their deficiencies, custodial institutions still retain countless individuals who could benefit from outright discharge or transfer to a more "normalized" program of care and education in the community.[13] Failure to create a sufficient number of such programs perpetuates warehouse-like institutions and produces an incalculable waste of human and economic resources.

Expectations that retarded and other developmentally disabled persons can live successfully in the community are displacing the self-fulfilling prophecies of hopelessness and despair which institutionalization usually reflects. Recent judicial decisions as well as similar cases now pending, embody this new sense of optimism. This litigation articulates two basic reforms. Mandatory provisions for the suitable education and training of all handicapped children will require that opportunities for such education be offered largely in the schools in the child's own community. *Mills*, and *Pennsylvania Association for Retarded Children v. Pennsylvania,*[14] represent successful challenges to contrary policies and practices. *Wyatt* and other right to habilitation cases question the necessity for and desirability of commitments to impersonal institutions and focus on the availability of less restrictive and more humane alternatives.

MILLS V. BOARD OF EDUCATION: IMPLEMENTING THE RIGHT TO EDUCATION

On September 24, 1971, seven school-excluded children and their parents, and Congressman Ronald V. Dellums, a local clergyman, and the D.C. Family Welfare Rights Organization filed the *Mills* class action. The named plaintiffs were children merely labeled as mentally retarded, behavioral problems, emotionally disturbed, hyperactive, or otherwise impaired, who were excluded entirely from educational programs. Numerous formal or informal devices and practices, such as waiting lists, indefinite suspensions, refusals to enroll, use of homebound instruction, conditional, unofficial suspensions, and delay in evaluation procedures had made such exclusions possible. Plaintiffs sought to require the District of Columbia, the Board of Education, the Social Service Administration and its public residential institutions to end their practices of denying handicapped and "disciplinary problem" (and any other) children their opportunity for publicly-supported education.

On December 20, 1971, Judge Joseph C. Waddy preliminarily ordered Defendants to (1) provide named-plaintiffs with a publicly-supported education suited to their needs; (2) provide plaintiffs' counsel with a list of names of every school age child known not to be attending a publicly-supported educational program because of suspension, expulsion, exclusion or any other denial of placement; (3) initiate efforts to identify remaining members of the class not known to them; and (4) consider, with plaintiffs, the selection and compensation of a master who would determine the proper placement of children in contested cases.

In this final opinion, granting plaintiff's summary judgement Judge Waddy found that the statutes of the District of Columbia, the regulations of its Board of Education, and the Constitution of the United States guarantee a publicly-supported education to all children, including all "exceptional" children. The Court held that defendants' conduct, in denying these children any access to a publicly-supported education while providing such education to other children, violated plaintiffs' rights to equal protection of the law. These children, the Court further found, were suspended, expelled, or reassigned from regular specialized instruction without any prior hearing and without any periodic review thereafter. Due process of law, the Court declared, requires a hearing prior to exclusion, termination or classification into a special program.

The Court rejected the Defendants' contention that they were unable to provide publicly-supported education for all "exceptional" children because of insufficient funds, stating that: "The inadequacies of the District of Columbia Public School System, whether occasioned by insufficient funding or administrative inefficiency, certainly cannot be permitted to bear more heavily on the 'exceptional' or handicapped child than on the normal child."

The District of Columbia was ordered within 30 days, to evaluate the educational needs of all identified plaintiff children and to offer them appropriate educational facilities. Such placements could be to a regular public school or to an adequate alternative including special education or tuition grant-supported private education. The school system was also directed to implement constitutionally adequate hearing procedures for placement or transfer of exceptional children. Furthermore, no child was thereafter to be suspended from school for more than 2 days without a prior recorded hearing before an independent hearing officer. At both the disciplinary and special education placement hearings, the child and his parents have the right to representation by counsel, to examine the child's records, to compel the attendance of school officials who may have relevant evidence to offer, to cross-examine witnesses and to introduce evidence of their own. Elaborate notice requirements are set forth for identifying all class members and informing all residents of the District that all children have a right to a publicly-supported education suited to their needs and of the procedures for enrolling children in an appropriate educational program.

The District was further ordered to produce a written, comprehensive plan for providing special education facilities and compensatory education programs and identifying those children who need such services within 45 days. If the school system failed to comply with these orders, a master would be appointed to implement the judgment and decree.

In the District of Columbia, the children affected by the decree include all exceptional children and all normal children subject to possible suspension or misclassification. There are an estimated 22,000 retarded, emotionally disturbed, blind, deaf, and developmentally disabled children in the District, and yet, as many as 18,000 of these children are not being furnished with programs of specialized public education. Furthermore, the exclusionary practices cited in the *Mills* decision occur throughout the nation.[15]

INEQUITIES IN THE DELIVERY OF SERVICES TO THE DEVELOPMENTALLY DISABLED

Just as developmental disability occurs in all classes of society, inadequacies in developmental disability services affect all classes, but with varying degrees of severity. In most communities, for example, the affluent can elect to pay the high cost of quality private education for a disabled child. Those of moderate income, who are not able to pay these costs, often find their children misplaced in classes not suited to their child's learning capacities. Those who are poor may find their children wholly excluded from publicly supported schooling. Because these parents will lack the resources–financial and informational–to place them in the private schools, their children often remain at home and go unschooled as public institutions default in their obligations.

Recent studies by the President's Committee on Mental Retardation disclose a higher incidence of mental disabilities in areas in which the rural and urban poor reside than in other parts of the country.[16] Such a result is, in part, attributable to the cumulative disabilities imposed on lower income persons. For example, one of the known causes of mental retardation is malnutrition.[17] Likewise, the eating of lead paint by children, a serious environmental hazard in slum tenements, can cause permanent brain damage and retardation.

Poor children also face increased risks of educational misclassification. Too many of these students are thought to be organically mentally impaired by their teachers and school psychologists when they are not, in fact, so handicapped.

Standardized intelligence testing contributes to erroneous diagnosis when such tests are biased against the culture and experience of minority group children.[18] The overall result is a remarkably high percentage of improper educational classifications for the children of the poor. Many are denied suitable services because their real disabilities remain unidentified, and untreated; no less disadvantaged are the many who are not in fact retarded, but who are nonetheless assigned to inferior "special edcuation" programs which tend to propel children toward the self-fulling prophecies of failure.

LITIGATING THE RIGHTS OF THE MENTALLY DISABLED

Reform based upon litigation on behalf of the mentally disabled has proved effective because, *inter alia,* of care in formulating issues and thorough trial preparation. Unfortunately, today's initial courtroom successes must be measured, in terms of wasted lives, against a background of legislative and administrative intransigence.

The goals of recent lawsuits[19] have long been sought by parent associations, professional organizations, and others concerned with the lives of the retarded. Central to the habilitation process, according to these advocates and professionals, is the concept of normalization, of minimizing deviations from the norm in treating the retarded. Within this conceptual framework, habilitation services should be made available to each person who is certified in need of them, in programs available, where necessary, at public expense and located, when possible, in the community in which the family resides. The adequacy of these programs, depends upon periodic evaluations which accord with objective professional standards. Furthermore, the needs of persons enrolled in such programs must be constantly reviewed so that meaningful habilitation plans may be formulated and carried out. If the retarded person resides in a state institution, this review should include a periodic, multi-disciplinary diagnostic evaluation; such evaluations should describe the habilitation setting of choice for each individual. On the basis of these individual reviews a state's overall mental retardation services plan may require revision to ensure delivery of the most appropriate services and facilities to consumers.

These propositions raise a number of legal issues of critical concern to the retarded. Is a state legally required to include all eligible persons in developmental assistance programs, and are such programs to be 1) community-based, 2) supported wholly at public expense, 3) periodically reevaluated, and 4) operated in conformity with professional standards?

Must placement in such programs be preceded by 1) an appropriate, comprehensive evaluation, with 2) specific notice of any proposed placement, 3) an opportunity for further independent evaluations, and 4) a due process hearing to resolve any objection to a proposed placement? Moreover, must such a placement reflect scientific knowledge as to the least restrictive habilitation setting suited to the individual's needs, proceeding along a spectrum of habilitation settings which range from assignment to regular education with supportive services, to full time special education classes, to small congregate residential facilities offering comprehensive care and habilitation programs?

The emerging case law is generally requiring that each of these questions be answered in the affirmative.

CONCLUSION: TOWARD EQUAL JUSTICE FOR THE UNEQUAL

The movement for social and legal justice for the developmentally disabled is approaching a new, perhaps more subtle, phase. Constitutional rights which have been formulated must now be more widely applied. Cases have been won in the courts; they must now be implemented on the back wards and in the classroom. Procedural safeguards and substantive requirements have been established which will require an infusion of new personnel if they are to work. Perhaps most important, out of greater awareness of institutional conditions, public sympathy and interest may be developing. Can this sympathy be converted into a base of support for the less spectacular concerns and problems of the mentally impaired? And, can litigation help to instill in the American public new attitudes towards and expectations for the mentally disabled and a belief that such persons should remain in our communities?

Certain preconditions are essential to effectively safeguard the human rights of the developmentally disabled. The rights to which these citizens are entitled must be clearly and specifically set forth in coherent and humane laws, regulations, policies and procedures.[20]

Litigation alone cannot eradicate the effects of decades of neglect and complacency. Nor can it offer final answers to such issues as the full range of habilitation services to be publicly provided, or the techniques by which the individual's need for such services can be accurately determined and appropriately delivered. Civil actions, however, offer disabled persons and their allied devices for publicizing, legitimizing and organizing around certain grievances. Given the barriers to their participation in electoral processes, the mentally disabled may need to seek judicial redress to challenge an intolerable and long-ignored *status quo*.

For the incipient processes of reintegrating the retarded into society to flourish, several basic reforms are essential. First, the federal role in this process must be greatly augmented. The Secretary of Health, Education and Welfare is empowered to enact a variety of guidelines for programs administered by that Department. Sorely needed, for example, are regulations in the educational aid programs which would require school systems across the country to initiate a zero-reject system of education and to otherwise protect the constitutional rights of the handicapped articulated in *Mills*. The federal government should also set guidelines, modeled after those in the *Wyatt* decree, to ensure, both quality residential care for the retarded and the movement of persons now in custodial settings to appropriate community-based facilities and services. Second, if mandates of change are to be vigorously carried out, new professional roles must be articulated and performed. Unless more mental retardation professionals are trained to serve in consultant, special master, or other change-agent capacities, and more attorneys and lay advocates are recruited to provide representation for the many developmentally disabled persons in need of it, efforts to implement the rights of the mentally disabled will be considerably undermined. Third, some of these manpower shortages can be partially offset by greater organizational activity in formulating and publishing professional standards and guidelines for the delivery of specific habilitation services. Vitally needed, for example, is a manual, designed for educators and parents of exceptional children, which sets out approved practices for the evaluation and periodic review of such children. Fourth, and most significantly, the growth of entitlements for the developmentally disabled should provoke a reconceptualization of the disabled person's place in our society, and the civil and human rights which he or she ought to more fully enjoy. Such a reformulation not only requires revision of existing laws and practices in accordance with new scientific knowledge, but also entails greater responsibilities to communicate such knowledge to the general public. Without such communication, the successful reentry of the retarded into the mainstreams of their communities will be considerably delayed.

Perhaps, as Dostoyevsky said with prisoners in mind, the measure of a society's degree of civilization is to be found in the care it affords its most disabled members. Unfortunately, custodial approaches to the needs of the retarded which did not develop suddenly in this country, cannot be expected to be eliminated instantaneously or effortlessly. But the era of human warehouses, at least for the retarded, is hopefully drawing to a close. Legal activity is apparently hastening that end. Too many retarded persons have needlessly endured lives of suffering, waste and oblivion for society to tolerate any other outcome.

Our present laws, scientific knowledge, and sense of conscience compel us to reexamine a system which has often chosen to incarcerate rather than habilitate. Toward that objective the advocates of the retarded seek to give voice to the pains of the silent, and to make possible lives of dignity and productiveness for the humble. Out of their present dependency, developmentally disabled citizens ask only for opportunities for self-help. *Mills* and *Wyatt* suggest that the courts will not be unresponsive to this petition. It is time for executive and legislative actions no less responsive.

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[1] President's Committee on Mental Retardation, *MR 70: The Decisive Decade*, (U.S. Government Printing Office, 1971) at 1.

[2] Weintraub, Abeson and Braddock, *State Law and Education of the Handicapped:* Issues and Recommendations (1971) at 7.

[3] 348 F. Supp. 866, (D. D.C., August 1, 1972).

[4] 344 F. Supp. 387, (M.D. Ala., April 13, 1972). 325 F. Supp. 781, 334 F. Supp. 1341 (1971); on appeal as *Wyatt v. Aderholt*, No. 72-2634.

[5] Mills v. Board of Education, 348 F. Supp. at 878.

[6] *Wyatt v. Stickney*, 344 F. Supp. 387, 390. Habilitation is defined in the Court's Order, as:

> The process by which the staff of the institution assists the resident to acquire and maintain those life skills which enable him to cope more effectively with the demands of his own person and of his environment and to raise the level of his physical, mental, and social efficiency. Habilitation includes but is not limited to programs of formal structured education and treatment.

[7] *Id.* at 393-394:

> A few of the atrocious incidents cited at the hearing in this case include the following: (a) a resident was scalded to death by hydrant water; (b) a resident was restrained in a straight jacket for nine years in order to prevent hand and finger sucking; (c) a resident was inappropriately confined in seclusion for a period of years, and (d) a resident died from the insertion by another resident of a running water hose into his rectum. Each of these incidents could have been avoided had adequate staff

and facilities been available.

[8] *Pennsylvania Association for Retarded Children v. Pennsylvania*, 343 F. Supp. 279, (E.D. Pa., May 5, 1972); 334 F. Supp. 1257 (1971).

[9] *Ricci v. Greenblatt*, C.A. No. 72-469F, (D. Mass., February 11, 1972).

[10] *Wyatt v. Stickney*, 344 F. Supp. at 389 note 2:

> Mental retardation refers generally to subaverage intellectual functioning which is associated with impairment in adaptive behavior. This definitional approach to mental retardation is based upon dual criteria; reduced intellectual functioning and impairment in adaptation to the requirements of social living. The evidence presented reflects scientific advances in understanding the developmental processes of the mental retardate. The historic view of mental retardation as an immutable defect of intelligence has been supplanted by the recognition that a person may be mentally retarded at one age level and not at another; that he may change status as a result of changes in the level of his intellectual functioning; or that he may move from retarded to nonretarded as a result of a training program which has increased his level of adaptive behavior to a point where his behavior is no longer of concern to society. See United States President's Panel on Mental Retardation, Report of the Task Force on Law, 1963.

[11] According to HEW, an estimated 7 million of these disabled persons are children. U.S. Department of Health, Education and Welfare, *Programs for the Handicapped* (Bureau of Education for the Handicapped, Office of Education, 1970).

[12] See, e.g., *Townsend v. Treadway*, C.A. No. 6500 (M.D. Tenn., filed February 16, 1972).

[13] President's Committee on Mental Retardation, *MR 69: Toward Progress*, U.S. Government Printing Office, 1969) at 6-7. Hindering the release of such persons, according to the PCMR, is the reality that in many communities:

> . . . services for the retarded are inadequate or almost nonexistent because agencies will not act, are unable to cooperate, or are prevented from acting by policies, procedures and lack of funds that restrict their development of services.

[14] *Supra*, note 8.

[15] For an informative discussion of school exclusion practices, see Regal, Elliott, Grossman and Morse, "The Systematic Exclusion of Children from School: The Unknown, Unidentified, and Untreated" (1971) (U.S. Office of Education Grant 0-70-3126 (603); Informally reprinted by The Council for Children with Behavioral Disorders.) These educational experts concluded:

> Through legal, quasi-legal and extra-legal devices or through apathy, schools cause, encourage and welcome the lack of attendance in school of millions of American youngsters. Such activity by the education system serves as a denial of civil rights as massive as the separate school systems maintained by law in prior years.

[16] President's Committee on Mental Retardation, *MR 69: Toward Progress* (U.S. Government Printing Office, 1969) at 8-9. ("No estimate of mental retardation incidence in [urban and rural low-income] neighborhoods is less than twice the national average.")

[17] President's Committee on Mental Retardation, *MR 70: The Decisive Decade*, (U.S. Government Printing Office, 1971) at 4-7.

[18] See, *e.g.*, *Larry P. v. Riles*, C.A. No. C-71 2270 RFP (N.D. Cal., June 20, 1972), 41 U.S.L.W. 2033, granting preliminary relief to black elementary school children placed in Educable Mentally Retarded Classes, who claim that they are not mentally retarded and that such educational placement violates their rights to equal protection of the laws.

[19] "Right to education" suits for various types of handicapped children have been filed in at least 14 states. These include California, Delaware, District of Columbia, Illinois, Louisiana, Maryland, Massachusetts, Michigan, New York, North Carolina, Pennsylvania, Utah, Virginia, and Wisconsin. "Right to habilitation" or "right to treatment" suits have been brought in Alabama, Georgia, Indiana, Massachusetts, Minnesota, Nebraska, New York, North Carolina, South Carolina and Tennessee.

[20] See, for example, Senate Bill S.3759, 92d Congress, 2d Session, introduced by Senator Javits and 21 other United States Senators which seeks to provide, *inter alia*, for the humane care, treatment, habilitation and protection of the mentally retarded in residential facilities through the establishment of strict quality operation and control standards and the support of the implementation of such standards by Federal assistance.

[21] Organizations involved in litigation and law reform activities in behalf of mentally handicapped persons include NLADA National Law Office, Washington, D.C.; Mental Health Law Project, Washington, D.C.; National Center for Law and the Handicapped, South Bend, Indiana; Harvard Center for Law and Education, Cambridge, Massachusetts; and Patient Advocacy Services, St. Louis, Missouri.

Part VIII
Delivery of Services

Editor's Notes

The complexity of structuring a comprehensive system for delivering services to the developmentally disabled has long baffled social planners because of the numerous ways in which the individual's handicap impacts on his daily life and the jealously guarded prerogatives of a wide range of specialized and generic agencies dealing with DD clients.

Edgar W. Pye describes several distinct models of delivering services to the developmentally disabled including the hospital/institutional approach and the regional center or community-based model. He discusses some of the hazards inherent in any effort to deliver services to the developmentally disabled and closes by listing the essential elements in an effective DD delivery system.

A different perspective on improving the delivery of residential and community services for the developmentally disabled is offered by Kenneth G. Crosby. He reviews the principles and purposes underlying the organization of the Accreditation Council for Facilities for the Mentally Retarded and the process of developing a set of standards for the operation of public and private residential facilities for the retarded. He outlines how the new accreditation process works, emphasizing the Council's commitment to measuring outcome rather than program inputs. The author also mentions that the Council is presently actively engaged in developing standards for community agencies serving the mentally retarded and developmentally disabled.

Harold L. McPheeters examines some of the emerging trends and problems in the administration and operation of services for the developmentally disabled and explores their implications for professionals in the field. He mentions the impact of recent court decisions, the move to community based programs, the serious moral dilemma presented by new technologies, and the trend toward integrated human service delivery systems. The author also notes the need to improve consumer involvement, apply the techniques of management by objective and management information systems and make more effective use of human resources in administering programs for the developmentally disabled.

Cooperation between the public and private sectors in serving the developmentally disabled is the topic of a paper by Rolf Williams. Noting the growing interaction between government and voluntary agencies, the author suggests two primary roles private organizations can play: direct provider of service and community advocate. He predicts that we will see more and more voluntary agencies assuming primarily an advocacy role in the near future. Williams also offers practical advice to private agency volunteers and professionals in dealing with government administrators.

Models of Service Delivery

Edgar W. Pye

INTRODUCTION

Mark Twain once said that it is right to do good and it is right to tell others to do good – and much easier! That we intend to do both is apparent by the convening of this conference.

The example of this conference as assembled today and concerning itself with the many facets of essential services and facilities for the developmentally disabled marks a milestone in our efforts to unite in achieving a higher level of services. In my remarks, I would like to: (1) postulate certain concepts that I see essential as a sound basis for a service delivery system; (2) describe and compare several delivery systems now in current use; (3) elaborate on the hazards inherent in any system that we may devise; and (4) point up those elements that I feel are necessary within any viable system, regardless of its auspices, sponsorship, or location.

My assumption is that we agree that all persons, regardless of their needs or special categorical distinction, have a potential for achievement and have a right to the services necessary to maximize their abilities. Thus, if we are to talk about models of service delivery we must begin with the environment into which the individual is born, namely, his community, and there to seek to reinforce that community with ideas and resources so that the delivery of human services can be enriched and augmented. This effort will be aimed at all persons, including persons with special needs. Unfortunately, this approach has not in the past been our community organizational pattern. Today we are beyond that period when we sought but one solution to the problem of the developmentally disabled. We have progressed to the point at which we see our primary responsibility for this population (estimated conservatively to encompass more than 20,000,000 persons) as that of determining how best to apply the human resource systems, which theoretically are available to our entire population, and to then make these increasingly available to the developmentally disabled. These persons too long have found themselves in no systems, or haphazard substandard systems, or in separate and segregated substandard systems.

We are aware that the very nature of man's search for solutions promotes fragmentation of effort and diversity of standards. It has been easier to classify individuals into categorical groups and try to make them fit the taxonomic grouping than to individualize programs to fit the needs of people. Our history is replete with examples of this mechanical approach to planning for human beings, which exemplify the heavy costs such ill-planned systems can incur by preventing utilization of the potential for achievement in even severely handicapped persons. Our history is also overburdened with examples of how delivery systems devised as solutions have robbed the individual of his basic rights as a free man as well as his dignity to move as an equal in his community.

It is appropriate, I feel, that we are examining the composite delivery system here in Washington. In examining models of service delivery we are continually reminded of the confusion that has existed, and I regret to say still exists, within governmental bodies as to just where concerns relating to developmental disabilities belong. Mental retardation, cerebral palsy and epilepsy have been tossed from federal bureau, to division to department and back, and as a result consistent planning efforts toward bringing this population into the mainstream of governmental planning efforts for all its citizens has suffered. The same pattern has regrettably been seen at the state and local governmental level partially as a result of this confusion. Visibility of the needs of this group has been possible only through the continued efforts of consumer groups whose labors we must applaud most heartily.

The result of this fragmented approach in planning for the needs of a large segment of the population is still visible at most jurisdictional levels. There remains a lack of consistency, direction, and commitment as to what developmental disability planning is all about, and what positive steps can be taken to move this population into human resource services systems that are available for all persons in our society. This conference, with its ties to leaders in the State councils, has for the first time the opportunity to set in motion the beginning of planning for a new era for those persons heretofore relegated to a lesser and a more segregated role in the community in which they live.

In looking at service delivery systems presently operative for the developmentally disabled, I am using the word "model" to represent a method for delivering services to the population concerning us, as distinguished from a standard of excellence. The day may come when such a model of perfection emerges, but I, as one of the many striving to perfect a better system, realize that day is still far ahead of us. In the meantime, we who are tied to a particular model continue to work toward changing it, perfecting it, and to work towards its ultimate replacement as our clients' needs are met within the generic delivery system in the community.

Perhaps the most evident and prominent and the most controversial model that is before us today takes form in what is described as the state hospital. Much has been written about this system, and what is both right and wrong with it. Needless to say it is easy for one to place all the blame for the failure of this system on particular theories of those eras; on simplistic solutions; on once-held values of segregation now outmoded. Whatever the reason for the failures in the past, efforts are being extended in the present, looking toward a new day, when the state hospital will hopefully be retooled and redefined as an integral part of the continuum of community services necessary to provide the ingredients for making a more complete and enriched life for the individual concerned.

In some areas of this country we are spending great effort in retooling and repairing an old and archaic segregated system. Many persons question whether such effort is worthwhile. As a Californian I am always alert to the architectural soundness of a building in view of our susceptibility to earthquakes. Buildings that are basically structurally sound can be repaired even after a good shake by the gyrations of the renowned San Andreas fault. However, those whose foundations are of questionable strength must be torn down following the tremor. It is faulty to attempt to patch or jury-rig these in expecting them to become functional once again. Thus it is I feel with state hospitals. We have had the earthquake! There are those systems which can be moved in the direction of being a part of the mainstream of services for all the developmentally disabled and which can be seen in their service outreach as participants with the community in bettering the life of the individual. There are others, however, whose basic structure is too frail to tolerate change; and planners and technicians must be honest enough not to allow themselves to be distracted from their main responsibility by trying to perpetuate those misconceived systems that should be abolished. Name changes, decentralization, new intake policies, geographic moves or other such devices to effect change will not suffice unless there is a commitment from leadership at all levels that the facility must provide a program geared toward the client receiving that help which will assist him in functioning most effectively in whatever community he lives.

The state hospital as a system has been a great teacher. We have learned therefrom that isolation, segregation, and separation are not positive forces for growth of an individual. This system has also taught us that attention to and support of an individualized program directed to the needs of a handicapped person can result in that person moving toward more independence and less dependence. It has shown us that program needs can be provided by a variety of resources not always located within institutions. It would appear our task is now to build on what is good within this model's experience, and to use the reservoir of resources and experience that is residual to set the stage for a new system which speaks to the rights and dignity of the individual.

In several areas of the country there has emerged a new delivery system which is built upon understanding the past problems of isolated campus living as epitomized by the state hospital. This new system has projected the public role in the provision of services to the developmentally disabled through a new model based in the community. Both Connecticut and California have moved in this direction and have described their service model as a *Regional Center.* There are common elements in both models which have assisted each program in enabling persons with handicapping conditions to secure services heretofore denied them. Perhaps the most obvious similarity is the establishment of a fixed point of referral, called the Regional Center, to which individuals and their families can turn for referral to the resources or services within the community which are most appropriate to assist them in meeting identified needs. The philosophical basis of both models is the right of any individual to have options in securing specialized help needed. The old concept that led families to collapse before the state initiated some kind of program, namely, state hospital admission, is eliminated by the Regional Center model. Both models also provide an advocacy system whereby the family and the individual are not only helped in considering various alternatives, but they are provided assistance in securing and nailing down the appropriate program. In both Regional Centers it is possible for the client to secure an essential service from the most suitable system for a defined need. We in California try to ensure that the health care comes from the private physician who is often the same one who provides health care to the rest of the family. Medical staff of the Center then provides the back-up consultation when necessary. Another positive aspect of the Centers system is its ability to go into the market place and secure a variety of services related to agreed upon needs rather than handicapping conditions. It is not uncommon for a client of a Center to be the recipient of an assortment of services having no identification with what have often been thought of as traditional handicapped services. Both Centers pride themselves in ongoing counseling services being made available to the individual and his family for the lifetime of the handicapped person. Through such close relationship, the Center staff becomes an integral part of the planning process, working very closely with the family and the client for his best welfare. Through guardianship service which becomes effective upon the death or incapacitation of the parent, the California Regional Centers may, by the will of that parent, be able to continue the "wise parent" role.

There are variations in the two Center models that need to be highlighted in order to perceive the total dimension of the Center concept. In Connecticut the Center is operated in various parts of the State as a state agency, and offers services such as residential, day care, and social service programs. In California the 13 Regional Centers are operated by various private health agencies under contract, renewed annually, with the State of California Department of Public Health. Thus, the employees of the Center in Connecticut are State employees, whereas in California all are hired under the rubrics, conditions, and standards of a private agency. California established its Centers expressly in this fashion thus giving the staff freedom and incentive to act in an advocacy role which they felt would have been difficult to effect had they been constrained by their ties to a State system.

A second difference between the two types of Centers lies in the manner in which services are provided to the client and family. In Connecticut the Center operates facilities in maintaining beds, whereas in California we believe that those who designate a service or prescribe a program should not be delivering that program. We feel the flexibility and freedom we have to monitor the service provided the client is greater in our having no direct tie to the service system. In fact our basic commitment to a community organization approach in initiating, upgrading, evaluating and retooling services and programs would be greatly restricted were we tied functionally to the system that was providing the service. In the Regional Center with which I am affiliated, the agency contracting with the State for the operation of the Center is San Francisco Aid Retarded Children, Inc., whose policy and philosophy of operation is the Center direction and goal. Perhaps one final area of difference needs stressing. Although both type Centers have funds to purchase services for clients from individual programs, Connecticut, through its provision and operation of residential and day care programs, uses its own services and funds. In the California Center, services are purchased in the community from the private operator or provider when no alternative sources for that funding are available. If the family can pay a part of the cost of program, through an agreed upon plan, the California Center pays the total cost and the family reimburses the Center. Such reimbursement augments the Center resources for the purchase of more services. In the near future, the California Regional Centers will also be required to purchase the services for clients placed in State hospitals, thus, placing the State hospital in a competitive position with the private sector.

The Regional Center concept is a new and exciting model of service delivery. There needs to be continued refinement, however, if it is to meet the total need of the population to be served. Connecticut's and California's experience will be used, I trust, by others who are contemplating change, not as absolutes, but as a base upon which they build their own system tailored to the needs as identified in their particular area.

There are other delivery systems which have merit and which have emerged in several areas which need mention here. The pattern in some of these is that in which the State or local community establishes conglomerate units, often residential, where resident clients live, work, recreate, and socialize. Some of these function as steppingstones to a broader community participation, while others totally ingrown, are known as life-time care living situations. The latter type often is seen in the so-called private community-based residential institution. The hazard here is that unless there is an advocacy component built in, there is a great danger of client reversion to the loss of identity and the loss of rights as often seen in the old state hospital model. Wisconsin has developed basic guidelines for what are called community living situations. These guidelines are refreshing and creative as they set forth philosophy, standards, staffing patterns, environmental and legal considerations. Such guidelines will serve as blueprints for communities and organizations concerned with community living situations for the developmentally disabled and will reinforce many of the principles heretofore expressed as essential if we are to see this population being served within the mainstream of services. Such guidelines, I trust, will be prepared for use in other areas of essential services such as work activity programs, recreation, and education.

I am happy to say an expiring model of service delivery is that one tied to a mental health system. Since mental retardation and other developmental disabilities are not necessarily associated with problems which fall within the province of psychiatry, it is inappropriate to include them in a system not related to their primary needs. The handicapped as well as the nonhandicapped population should have ready access to the mental health system as the need arises but need not be a part of that system as the source for provision of all other services to them.

POSSIBLE HAZARDS IN ANY DELIVERY SYSTEM

The following listing of observations and warnings may be considered in the establishment of an effective delivery system for the developmentally disabled:

1. The creation of a "Developmental Disability Authority" does not in itself result in the delivery of better services or more effective coordination. Quite to the contrary, it may preserve the same old unsatisfactory system under a new and attractive label.
2. Public monies allotted to a new concept can go toward perpetuation of an agency rather than being applied to client services.
3. The power inherent in any system to *provide* or to *purchase* may tend to sustain the familiar but outmoded fashion of service. Thus, the establishment of any new system, must have as its basis a clear-cut statement in terms of policy and philosophy as to goals and direction with the means to control, monitor, and evaluate compliance and performance.
4. In any new system committed to integration there is always the potential for the outgrowth of separate but equal services because of the fear by the consumer of being buried once again in a larger system. Integration, although agreed upon, may result in a centralization of authority to the point that the value of integration will be lost and the handicapped will again be segregated, but within a larger bureaucracy. Also, within an integrated system, there is still a danger that some handicaps may be more or less popular than others.
5. There is tendency in the formulation of a new delivery system serving as it does a misunderstood or unpopular population, that other categories of social problems will be "dumped" within the scope of the system even though there is little or no relationship between them.
6. The funding agents' agenda and philosophy for the system must be clearly stated, and understood in being compatible with the goals of the consumer groups.
7. In the first flush of creative zeal there is a risk that "new" models will be developed and tested which have already been tried and tossed aside. Let us not continually redevelop the wheel!

These hazards and others imaginable must be considered if we are to have a practical and viable system that is directed toward moving the developmentally disabled at any age, or handicap into the mainstream of community life.

ELEMENTS ESSENTIAL TO ANY DELIVERY SYSTEM FOR THE DEVELOPMENTALLY DISABLED

In summary, let me set forth a statement of key elements in the establishment of a delivery system in recognition of the rights of an individual, regardless of his handicap, to live within his own community, and to be served and to partake of those resources available to all residents in that community. These are listed below not necessarily in priority order:

1. The human rights of the person identified as developmentally disabled must be continuously observed and served.
2. Means and methods must be present within the system to enable

the client and his family to effect continued input into program direction.

3. The system must be located geographically to permit easy accessibility to the clients and families it serves.
4. The system must continually work toward guiding its clients into the mainstream of service resources available to all residents in the community.
5. Provision must exist for the system to be free to select the highest quality of service from any service sector. Whatever services and programs are selected must have built-in provision for continuity of service.
6. A realistic level of funding support is essential to carry out the overall objectives of the program.
7. An appeals procedure within the system must be available to the client at all levels.
8. An ongoing participation with community planning bodies (such as Comprehensive Health Planning) in order that integration of the needs of the developmentally disabled can be effected into the primary health and welfare delivery systems.
9. A method of early case-finding must be present with provision for entrance into accessible and necessary programs.
10. An advocacy component must be an integral part of any system.
11. A state political structure must exist that is responsive to the needs of all its citizens including the developmentally disabled.
12. Manpower training and development must be responsive to the continually changing needs identified by the system.
13. A recordkeeping system must be adequate, and record material easily retrievable and useable for planning and program direction, as well as being meaningful to the client's needs.
14. There must be a clearly defined goal-related evaluation system.
15. An effective method of educating the community as to the problems and needs of the developmentally disabled and its role and responsibility in overcoming the problems and providing for the needs must be devised.

As a matter of basic philosophy any system must pursue every opportunity to participate with parents, providers of care, and others in the enrichment of the lives of the handicapped. Moreover, it must continuously seek the ways and means to achieve its stated goals and toward that end invite the views and counsel of those who share in this important endeavor.

SUMMARY

The problems are many in the establishment of any service delivery system where human beings are concerned. We have struggled over the years in our search for better ways to do the job that needs to be done. Now the opportunity presents itself to work in concert in this age of ecumenism with one another to design and build that model that we conceive. Let us agree that with our state and national planning and advisory councils supporting this principle of innovation and integration, we as participants also will share our ideas to the end that the new systems we seek will emerge. The mechanism for communication is here. Let us use it!

WORKSHOP DISCUSSION

The items listed here are a summary of general comments by resource persons and participants.

(1) It must be recognized that funds dictate the level of "mainstream" services. Thus, persons who have problems in getting any services due to their handicap may have an even greater problem in securing necessary services from the generic systems.

(2) It is a problem to plan systems of service delivery when the dimension of need is unclear. We must know all the parameters.

(3) In any system cost efficiency factors must be considered versus a humanistic approach or system.

(4) Early case identification must be seen as an aid in cost reduction.

(5) Problems were described related to the development of a system that has a total commitment to all the developmentally disabled—not to only one segment of the population.

(6) An expression was made about the need for any service system to first consider individuals and their needs and develop the system around that rather than around the needs of the deliverer. Ultimately, any model should be evaluated by asking the question "are people getting service?"

(7) Pros and cons are discussed as to whether or not advocacy can best be offered from within or without the delivery system.

(8) The question was raised as to whether our society really believes in equality of service for its handicapped population; doubts were expressed by some.

(9) An expression was made as to barriers existent in delivery systems in the form of poor architectural design; misnamed organizations, such as, National Association for Retarded *Children* etc.

(10) There was much "show and tell" by various State representatives describing how they approached service delivery in their State. From Alaska with its unique problems, to Ohio with its new statewide case management protective service and personal advocacy system, and then on to the Atlantic Coastal States with their varied approaches and problems, the groups agreed that one model cannot serve all States. Each State must tool its system to meet its particular needs recognizing the hazards cited in the topic paper as well as considering the elements described as essential in any delivery system.

ACF/MR-JCAH Standards: Instrument for Development Of Quality Services

Kenneth Crosby

Let us begin by assuming that all persons responsible for providing services to the developmentally disabled want to provide high-quality, effective services. This assumption is justified, I think, because, in the first place, if the new concept of developmental disabilities is to be accepted and implemented, the services provided under the developmental disabilities legislation must be effective in meeting the needs of disabled persons. And, in the second place, most people, even as you and I, want, for a variety of reasons, to do a good job. Doing a good job, however, requires that we have some objectives against which we can judge our performance. Such objectives are often informal and unwritten. But if they are to be maximally helpful in assuring high performance, they must be precise and explicit, so that our attainment of them can serve as a measure of our achievement. Thus, in the performance of our day-to-day jobs, each of us actually requires a set of standards as a means of assuring quality performance, for a standard is nothing more than a practical objective, the attainment of which can serve as a measure of our progress or our success.

I need not, I am sure, belabor the point that the assurance of quality services demands standards, and the evaluation of performance against standards: the setting of standards and the measuring of performance against them are essential functions in the management of any enterprise, and the Developmental Disabilities Act already requires that each State Plan provide for the maintenance of standards with respect to the scope, quality, and administration of services under the Plan. I would hope, however, that the experience of the Accreditation Council for Facilities for the Mentally Retarded would be helpful in this regard, for the Council was established three years for the express purpose of establishing standards, and the means to assess compliance with standards, in order to improve the quality of services provided that portion of the developmentally disabled called mentally retarded.

The Accreditation Council for Facilities for the Mentally Retarded–AC/FMR for short–is a component of the Joint Commission on Accreditation of Hospitals, which has provided a national voluntary accreditation program for hospitals since 1951. The Council is composed of two representatives of each of its five Member Organizations: the American Association on Mental Deficiency, the American Psychiatric Association, the Council for Exceptional Children, the National Association for Retarded Children, and the United Cerebral Palsy Associations. Several other national organizations interested in programs for the developmentally disabled are currently applicants for Council Membership. One of the great strengths of the Council is the fact that it includes participation by both the professional providers and the representatives of consumers of services for persons with mental retardation and other developmental disabilities. The Council's whole reason for being is the improvement of services to the ultimate consumer.

UNDERLYING ASSUMPTIONS

The Council's standards, like all other standards, are based upon assumptions that either arise from cultural values, or depend upon the validity of the relationship between the accomplishment of an intermediate objective to the subsequent achievement of an ultimate goal. Since value assumptions are not subject to proof, but are either accepted or rejected by the user of standards, and since, in most areas of human service, the validity of the relationships between intermediate and ultimate objectives is frequently unproven, it is important that these assumptions be identified and understood. Among the assumptions underlying the Accreditation Council's standards are the following:

(1) The person with mental retardation (or another developmental disability) is first of all a *person* who has the same basic rights as other persons, including the right to adequate treatment and habilitation.

(2) The most useful way to view mental retardation is within a "developmental model," in which each retarded person is considered to be capable of learning, growth, and development, and each person is held to have some potential for progress, no matter how severely handicapped he may be. (Obviously, the developmental model of mental retardation is both consistent with and supportive of the developmental disabilities concept.)

(3) Services can and must be provided to meet the developmental needs of the disabled person throughout his life span, so as to maximize his human qualities, increase the complexity of his behavior, and enhance his ability to cope with his environment.

(4) Programs and services should be conducted in accordance with the principle of normalization, defined as the use of means that are as culturally normal as possible to elicit and maintain behavior that is as culturally normal as possible.

These and other underlying assumptions are stated in documents such as the Declaration of General and Special Rights of the Mentally Retarded, and the Policy Statements on Residential Services of the National Association for Retarded Children and the President's Committee on Mental Retardation; and the dependence of the standards on these assumptions is acknowledged in the standards documents.

PARTICIPANTS IN DETERMINATION OF STANDARDS

At this point in time we frequently lack data to show that compliance with standards is actually related to desired program outcomes (or the achievement of ultimate objectives). Such standards, therefore, can be derived only from a consensus of experienced leaders in the field as to what constitutes an adequate program. There may, moreover, be a number of means, or kinds of programs, that can achieve the desired result, and since it is the result that is important, standards should be applicable to diverse kinds of endeavors. For both reasons, participation in standard setting for human-service programs should be as broad and varied as possible, in terms of such factors as professions, viewpoints, program approaches, and levels of administrative responsibility.

In the case of the Council's standards, while the group of 10 people that presently constitute the Council is charged with adopting standards, it is obvious that they cannot, by themselves, possess the expertise required to develop standards for every kind of service needed by the retarded and developmentally disabled. Consequently, the real role of the Council is to enlist the help of many individuals and groups in developing standards, and from these efforts then to assemble a workable whole for the guidance and assessment of overall program adequacy. The Council's *Standards for Residential Facilities for the Mentally Retarded,* published in September, 1971, reflects the participation of more than 200 individuals–administrators, practitioners, researchers, and consumers–including representatives of 42 national professional and consumer organizations (in addition to the five Member Organizations of the Council). Thirty-five of these organizations, with a manifest major interest in the provision of services for the mentally retarded and developmentally disabled, have been asked to establish continuing formal liaison with the Council, so as to keep it advised of changing knowledge, needs, and practices relevant to standards setting and compliance testing. For as value and validity assumptions change, as data relating intermediate to ultimate objectives becomes available, and as program approaches and emphases are modified, the standards must also be revised in order to keep them effective tools for the improvement of services.

STANDARDS: ENVIRONMENT PROCESS OR OUTCOME?

Most assemblages of standards emphasize what may be called the "structure" of a program: the possession of an adequate physical plant, sufficient numbers of qualified personnel, and a sound administrative organization. Essentially, such standards, which have to do with intermediate objectives and are sometimes called "effort standards," relate to the environment in which services are rendered, rather than to the services themselves or to the outcomes of the services. The problem with such standards, of course, is that while environmental factors may *enable* adequate services to be provided, their presence does not *guarantee* that effective services will actually be delivered to the clients who need them. Stated another way, structural standards are *necessary* but *not sufficient* to assure an adequate program. If one wants to use standards as a means of ensuring the delivery of effective services, it is necessary to look at more than the environment in which those services are rendered.

Since an effective program is the ultimate objective, it is desirable, wherever possible, to define program outcome in such a way that it can be addressed directly in standards. If it is agreed that, whatever else they may do, programs for the mentally retarded and developmentally disabled must produce increments in the adaptive behaviors or developmental skills of their clients; and if it is further agreed that these behaviors and skills can be measured at some acceptable level of reliability; then there is, in principle, no reason why standards should not focus directly on outcome. The AC/FMR standards do require the facility to provide each client with services that enhance his development. They demand for each client an evaluation that identifies his particular developmental needs, implementation of an habilitation program specifically designed to meet those identified needs, regular review of the client's response to that program, and appropriate revision of the program consequent to the review to ensure that program objectives are achieved. The specific objectives of each individualized habilitation program must be stated in behavioral terms, so that their achievement can be assessed; general, hoped-for goals, however worthy they may be, are insufficient for program evaluation.

If it were feasible or desirable to ignore the means by which outcomes are achieved, it would be possible to limit standards for services to the retarded and disabled to outcome measures alone. Not all of the possible means to effective results may be consistent with underlying value assumptions, however. The normalization principle, for example, stipulates means as well as ends, and the achievement or elimination of behaviors through the use of aversive conditioning may not be acceptable when other methods are available. There are, moreover, data that validate the relationship of some program provisions to the achievement of desired program outcomes. There is, for example, excellent evidence that the development of mentally retarded persons in a residential setting is highly dependent upon the degree of positive interaction with nonretarded adults, and there is good reason to believe that certain aspects of the physical as well as the social environment are really important in achieving desired behavioral results. In the absence of universal knowledge of these factors, and the implementation of this knowledge in program design, it would be imprudent to ignore them in standards. Insofar as there is concern with means, therefore, it is necessary to include standards that relate to program process—the kinds of services that are delivered to recipients and the ways in which they are delivered—as well as standards that stipulate program outcome.

It is also sometimes possible to conceptualize and design intermediate objective standards as the outcomes or products of structure, rather than as structural or formal components. Thus, rather than stipulating the form of the administrative organization of a facility, one may specify and examine what the product of the organization is to be: the delivery of services to the clients. This approach is desirable whenever there are a number of equally acceptable means to a desired end.

The Accreditation Council is committed to developing and using outcome and process standards wherever possible. At our present stage of knowledge, however, some need for purely structural standards remains. With the limited techniques for performance assessment that are currently available, for example, it is frequently difficult to judge the quality of professional services. Requiring that such services be rendered by professionally qualified, certificated, and licensed personnel does not guarantee that they will be of high quality, but the probability of securing acceptable services is greater under this condition than it would be if less-than-fully-qualified personnel were used. Thus, the Council's standards do make this structural requirement.

Because standards concerning structure and process may have to include considerable detail, they may take up substantial space in a document such as the Council's *Standards for Residential Facilities.* No one should believe, however, that the amount of space occupied by a standard, or by a section in the standards document, is necessarily proportional to its importance in determining the adequacy of a program. A small number of outcome standards may be stated succinctly and require little space, yet be of crucial importance in the assessment of program effectiveness.

Whether they represent intermediate or ultimate objectives, standards must be expressed in such a way that their attainment can be objectively determined. Standards may represent the implementation of a philosophy, or they may require a philosophy to be implemented, but if they are to be useful in assessing the adequacy of programs, they must not be merely exhortations with which compliance cannot be judged.

STANDARDS RELEVANT TO ALTERNATIVE MODELS OF CARE

The 23 committees that wrote the Council's *Standards of Residential Facilities* were asked to develop standards that do focus emphasis on the delivery of development-enhancing services to each individual resident, without stipulating the organizational means or mandating any model of delivery. By focusing on the developmental services to be provided residents, whether by the facility itself or by other community agencies and resources outside it, the committees found it possible to write standards that are selectively applicable to the total range of facilities, from the large public to the small private. The Council's Standards are intended to be pertinent to improving services in the traditional institution, but without encouraging the perpetuation of the institution as *the* model for the delivery of residential services. Whether any mentally retarded person really needs the kind of care that only such an institution can provide remains an open question, and it is clear that standards should also be relevant to alternative models of residential care, and that exploration and innovation in this field should be encouraged.

It is also clear that the "total institution" described by Goffman and others must be avoided, and that such "total institutions" can be small as well as large, and physically located in the heart of a community as well as remote from it. Consistent with the principle of normalization, therefore, the Council's Standards emphasized affiliation of each facility with other community resources, and the use of community rather than only facility services wherever possible. By focusing on outcome and process rather than on structure, the Council's standards-writing committees realized that many services to residents may be provided as well or better by programs that are outside the facility itself. As a result, many of the standards for professional and special services, and for organizational, administrative, and programming policies and practices, are applicable to programs that do not provide residential services.

Some 9,600 copies of the *Standards for Residential Facilities* have been distributed in the year since their publication, and this, I think, does indicate the hunger that exists for standards that can help to assure the development of quality services.

The standards for residential facilities have served as a base for the development of standards for comprehensive community programs for the mentally retarded, specifically applicable to agencies providing less-than-24-hour services. These standards are being developed by a 26-member advisory committee, with the assistance of some 30 consultants, and they are expected to be published next year. They will, of course, reflect the same emphasis on the provision of individualized developmental services for each client in response to his identified needs. To promote continuity and integration of services, standards will be provided for "agency service components"—such as diagnostic and evaluation services, services to promote learning development, and services to support employment or work—rather than for specific programs that may be categorized in terms of age group or setting. The standards will not mandate any administrative or organizational model, but they will require each agency to seek participation in a comprehensive network of services, or service delivery system, that will ensure the delivery to each client of those services that he needs. Eventually, it is hoped that the Council will publish a single, comprehensive set of standards for all facilities and programs serving the mentally retarded, incorporating residential services as only one essential component in the complete continuum of care. The Council also intends to explore, during the coming year, the feasibility of accrediting a coordinated, comprehensive, community-wide system of services rather than merely accrediting individual elements in such a system.

Although the Council is entitled "for the mentally retarded," it is in tune with the developmental disabilities concept. Throughout the development of the Council's standards there has been a deliberate effort to include participation that would make the standards applicable to persons with cerebral palsy and other developmental disabilities, as well as to persons with mental retardation. It is likely that the Council's next publication will be titled "Standards for Community Agencies Serving Individuals with Mental Retardation and Other Developmental Disabilities," and that persons interested in programs for individuals with disabilities other than mental retardation will also find the Council's residential standards to be useful.

THE ROLE OF STANDARDS IN IMPROVING SERVICES

A well-developed set of relevant standards can be used in several ways to help to improve services. The standards can provide guidelines useful to agencies responsible for developing services and service delivery systems. They can provide the concrete information needed to enlist the support of legislators and the general public in making necessary resources available. They can serve to educate members of the various professions as to the kinds of services they should provide. They can guide the administrators and staffs of facilities and agencies in upgrading services, and encourage them to appraise the programs that they offer. They can assist consumers and consumer representatives in evaluating and monitoring the services that are made available to meet their needs and in initiating change where necessary. As a last resort, they can serve as a resource in the event that a court of law is asked to judge the adequacy of treatment received in relation to the treatment to which a recipient is legally entitled. And, of course, they can be employed in a formal accreditation program.

While standards may be used as a sort of checklist against which services are compared, their usefulness can be increased by defining systematic procedures for measuring the performance of programs relative to the specified objectives. The nature of these procedures is (or should be) dictated by the standards with which compliance is to be assessed, as well as by the particular purpose for which the assessment is made. Thus, the National Association for Retarded Children's project for Parent Training in Residential Programming (supported by the Division of Developmental Disabilities) has developed excellent materials to help parents judge the extent to which residential facilities comply with the Council's Standards. Highly systematic and standardized procedures are needed for accreditation, in which the degree of compliance must be determined. In any case, experience indicates that maximal benefit accrues when performance is evaluated both continuously by the program operators and at regular intervals by independent, impartial, outside observers. It is a truism that when we are involved in our own programs, we often cannot see the forest because of the trees, and we frequently lose sight of individual trees as well.

THE ACCREDITATION PROCESS

Self-Survey by Facility

For accreditation purposes the procedures to assess compliance with the Council's Standards begin with a complete self-survey, which is to be done by the facility's own staff prior to a site visit by Council surveyors. Since each item in the Standards has some degree of importance in a fully adequate program, the Survey Questionnaire used for the self-survey requires the facility to assess its compliance with every item in the Standards that is relevant to its particular operation. The facility is required to report whether it is in full compliance, partial compliance, or noncompliance with each item, or if an item is not applicable, and to explain each instance of partial compliance or nonapplicability. The facility is also asked to provide documentary evidence or expert certification of compliance with some items, and to answer questions concerning the implementation of certain items, or to give examples of their implementation. Like the required explanations of partial compliance and nonapplicability, these supplementary questions serve several functions. An answer may indicate whether or not the respondent has understood the statement of the standards, and it may permit an independent judgement to be made regarding the facility's compliance. Perhaps more important, it is easier to simply say, yes, we are doing what we are required to do, than it is to state what it is we are doing or how we are doing it, in relation to a specified objective. Having to do the latter causes us to think, and often to evaluate the rationale of what we may be doing merely from custom, or habit, or routine.

Council Prepares for Visit

Prior to conducting the on-site survey, the Council's surveyors review the facility's Survey Questionnaire, which constitutes the information base for the survey. Inquiries may be made of public licensing agencies, or other relevant examining or reviewing bodies, concerning the facility's compliance with standards. At the beginning of the site visit, an opportunity is provided for any representatives of consumers or the general public to offer any other information relevant to the determination of the facility's compliance.

Compliance with structural standards can usually be determined by review of the Survey Questionnaire, leaving the Council's on-site survey free to concentrate on observations of process and outcome. When standards emphasize product or outcome, as do the Council's, the on-site survey must focus on confirming the actual delivery of services to clients, and on the effectiveness of those services. One simply cannot judge compliance with such standards by examining a table of organization, computing alloted space, or counting the number of personnel, no matter how important these enabling factors may be. The time required to assess the delivery of services to every client of a facility may prohibit that approach, but at least a representative sample of clients must be investigated.

Site Visit

In conducting the on-site survey of a residential facility, the Council's surveyors concentrate on performing a "program audit" of a stratified sample of residents, of various ages and levels of retardation, both ambulatory and nonambulatory, in order to assess compliance with those items in the Standards that most directly pertain to the delivery of adequate programs and services to residents. The size of the sample needed depends, of course, upon the size and homogeneity of the facility's population, the consistency found as the sample is examined, and the desired level of confidence for the conclusions. (While full compliance can never be proven by a sample of any size, only one instance of less than full compliance is required to disprove full compliance for a population.) The surveyor's assessment is derived from reviewing the record of each resident in the sample; from observing the resident, in the living unit and in program areas; from talking to him (when that is feasible); and from talking with the direct-care personnel who are responsible for the resident's care. In respect to professional and special services, the surveyors assess both whether or not such services appear to be reaching the resident, in accordance with his needs, and whether or not such services appear to be reaching the direct-care, front-line staff, in accordance with their needs for training and consultation, so that they may more adequately meet the needs of the resident. The surveyors also assess the degree to which services seem to be rendered in a coordinated, interdisciplinary fashion, rather than in a fragmented, discipline-oriented way, and the extent to which the principle of normalization, as defined in the Standards, is implemented in the daily lives of the residents. Finally, the surveyors assess the ultimate measure of the facility's effectiveness: the trend in the resident's development during his stay there, as judged from the recorded assessments of his behavior and status.

You will note that rather than beginning, in a more traditional way, with the top administration and staff of the facility, the Council's surveyors begin with the resident, go to the direct-care staff who ordinarily spend most time with the resident, and then go to professional staff and administration, primarily to try to ascertain the reason for those instances in which needed services do not seem to be being delivered. As the last step in the survey process, the surveyors meet with the facility's administration and staff and review their self-assessment of compliance with the Standards, pointing out and discussing each instance in which the surveyors' assessment—derived from observations of individual residents and individual programs—differs from the facility's assessment relative to all its residents and all its programs. This exercise, which has required up to five hours, truly reveals the value of combining and self-appraisal of facility programs by facility staff with an appraisal by outside, objective, third-party observers.

Evaluation and Feedback

An accreditation survey by the Council requires from two to fifteen man-days, depending on the size of the facility. The survey is not an inspection. It is, rather, an evaluation, designed to provide the facility with impartial educational and consultative services that its own staff, no matter how well qualified, simply cannot offer. Each Council surveyor is an experienced and fully qualified member of one of the professions relevant to evaluation of and program planning for persons with mental retardation and other developmental disabilities. Each surveyor is, of course, trained in the Council's standards and in the procedures used to assess compliance with them, before undertaking a survey. The survey procedures are thoroughly tested prior to use, and feedback from the survey process is used to improve and refine the survey techniques, as well as the standards themselves.

At a recent national conference, one facility administrator, who had experienced both more traditional kinds of surveys and a survey by AC/FMR, stated his conviction that the latter was "infinitely more meaningful" to the facility's staff. A survey that focuses on process and outcome rather than on structure has another advantage, too, in that data concerning program effectiveness, compiled over time, can serve to validate standards concerning program structure. Once programs successful in achieving desired outcomes are identified, it may be possible to specify what inputs are really necessary for successful programs and, accordingly, to supply empirical justification for the effort requirements stated in the standards. The validity assumptions that necessarily underlie standards must be subject to continuous scrutiny and test, and the standards modified accordingly. Standards must, in other words, be continuously subject to review and revision on the basis of survey experience. Standard setting and compliance assessment are, therefore, really dual, complimentary aspects of a single process of accreditation.

LEVEL OF STANDARDS AND DEGREE OF COMPLIANCE REQUIRED

A dual-aspect problem in this process concerns the *level* at which standards are to be set and the *degree of compliance* that is to be required for accreditation. Two choices are possible concerning standards: they may be set at a level representative of some level of current practice, or they may be set at the level representative of current knowledge and belief as to what good and effective practice should be. It is generally agreed that in most areas of human service—and certainly this is true of services for the developmentally disabled—current practice lags far behind available knowledge. Since published standards inevitably serve as guidelines for the development of future programs, as well as measures of the adequacy of existing ones, it was the Council's decision that its standards should represent what the best available current knowledge and practice hold to be necessary or desirable for providing a fully adequate program. The participation of practitioners in standards development assured that every standard is currently being met in at least one facility, and so long as any facility can comply with a desirable standard there is no reason, in principle, why others should not do so, or why consumers should not expect them to do so, or why consumers should be satisfied with less. Considering the variable level of certainty with which compliance with intermediate-objective standards may be related to achievement of ultimate goals, however, the standards are divided into those believed mandatory or essential and those thought desirable or recommended, in order to provide a fully adequate program.

Once the level of standards has been established, the degree of compliance that is required for accreditation may be set at the level of compliance exhibited by the least-complying member of the group, or number, of facilities one wishes to accredit; or it may be set according to some desired level of adequacy of program without reference to the number of facilities that achieve it. The degree of compliance may be established, in other words, so that any given proportion of existing facilities may qualify, or so that only those that provide a program defined as adequate may do so. The number of accreditable facilities, obviously, is a function of both the level of the standards and the level of compliance required for accreditation; and the determinations of these two levels, therefore, are inseparable interrelated.

The fundamental purpose of accreditation, as the Council views it, is the improvement of services to the consumer, and the level of required compliance must be set so as to best accomplish this result. Accreditation is also intended, however, to protect the consumer by identifying high-quality facilities, and both the required level of compliance for accreditation and the way in which accreditation is presented to the public must also realize this goal.

It may be argued that if accreditation is limited to the few facilities that provide the highest level of service, other facilities will not be motivated to improve their services so as to achieve the distant goal of accreditation, and that the most effective approach to improving services through accreditation, therefore, is to establish a level at which many facilities can qualify, and then raise the level so as to lead these facilities to improve their services in order to retain their accreditation. On the other hand, most leaders in the field would probably agree with a recent public statement of the Executive Director of the President's Committee on Mental Retardation that "very few" residential facilities for the retarded presently maintain "adequate standards of health and treatment," and it may be questioned that less-than-adequate facilities should be awarded the seal of approval that accreditation inevitably implies. If accreditation means to the consumer (or his representative) that he can feel some assurance of obtaining adequate services from an accredited facility, can accreditation of a less-than-adequate facility be countenanced? Finally, accredited facilities are likely to be taken as models for others to emulate, and should anything less than what the best current knowledge and practice allow be permitted to serve as such a model?

While discussion of this issue will undoubtedly continue, for the present the Council has taken the position that the bestowal of accreditation must attest to the demonstrated delivery of adequate, effective services to the residents of a facility. The fact that a facility applies for accreditation and voluntarily subjects itself to survey, however, is obvious evidence of its striving for excellence, whether or not accreditation is achieved, and every facility that opens itself to the Council's scrutiny deserves public recognition of this fact. The award of a certificate of accreditation is not, and should not be thought to be, the sole reason or motivation for applying for a survey. The council is studying, however, the possible advantages of providing for levels of accreditation, rather than only accreditation or nonaccreditation. It might be possible, for example, to recognize a less-than-full-accreditation status that would acknowledge the demonstrated effort and intent of a facility to offer adequate services, without implying to the consumer that adequate services are presently available from the facility, or inferring that the facility should be taken as a model that others may emulate. It should be noted, in this connection that all accreditation is conditional, in the sense that its retention is dependent upon continuance of compliance with the standards and upon annual or biannual resurvey; and during each resurvey, attention centers on improvements accomplished since the previous assessment.

INDEPENDENT, NATIONAL, VOLUNTARY ACCREDITING BODY

It should be apparent from the preceding that if standards are to be effective in ensuring quality services, the body that sets standards and required compliance levels must have the flexibility to change standards and levels in response to changing knowledge, conditions, and needs, and especially in response to experience with the application and use of the standards. The standard-setting body must also have the flexibility to assure appropriate participation in standards development, review, and revision. Governmental licensing, primarily concerned with the availability of essential environmental factors, and intended to assure minimum capability to offer services to the public, is surely relevant to consumer protection. The flexibility necessary for setting and maintaining effective, detailed, programmatic standards, however, is more likely to be possessed by a voluntary than by a governmental agency. The Council therefore believes that such standards are best set by an *independent, national, voluntary accrediting body,* composed of representatives of both the providers and the consumers of the services covered. Through this unified approach, also, the inefficient proliferation of standards can be avoided. The accreditation awarded by an independent body, attesting that a facility meets relevant standards, may, of course, be recognized by government, as, for example, in certifying eligibility for participation in public financial programs. Even if accreditation is not achieved, a survey may provide evidence that supports the efforts of publicly-operated facilities to secure needed changes or increased resources from legislative bodies. Consumers can assist facilities in this regard by encouraging their participation in the accreditation process. Facilitation of cooperative relationships with university and other professional training programs, which are themselves linked to voluntary accreditation, is yet another way in which accreditation of a facility may help to upgrade its services.

SUPPORT FOR THE AC/FMR

All these approaches are anticipated in the program of the Accreditation Council, which represents a partnership of providers and consumers, actively supported by government, and working together to improve services to the mentally retarded and developmentally disabled. Since its formation the Council has been financially supported by the Social and Rehabilitation Service of the Department of Health, Education, and Welfare (with current grants from the Division of Developmental Disabilities), by contributions from each of its five Member Organizations, and by contributions from the Joint Commission (whose Corporate Members are the American College of Physicians, American College of Surgeons, American Hospital Association, and American Medical Association). Fees paid by facilities and agencies participating in the accreditation process partially defray the costs of the survey. All relevant sectors thus share in the Council's commitment to develop and implement standards and survey procedures that will ensure the delivery of quality services to persons with mental retardation and other developmental disabilities.

Using these techniques, accreditation can protect the consumer by identifying high-quality facilities, encourage providers to maintain high levels of service for the consumer's benefit, and furnish the facility or agency with evidence of accountability to those organizations and individuals who support it, and whom it serves.

New Skills Required As A Result of New Problems in Administration And Service

Harold L. McPheeters, M.D.

In the past few years, several new concepts and problems have emerged in the administration and delivery of services for the developmentally disabled. It is no longer possible for planners and administrators to be concerned with only a single traditional kind of program; they must also be aware of the wide field of social forces in which they operate, and they must have the skills to deal with many aspects of that broader field of forces in greater depth than previously. Before identifying some of the new skills required, it may be well to first explore some of the new trends in the delivery of services and in administration. First let us look at some of the new trends in services, for example, court decisions on "Right to Treatment or Education."

A notable recent trend has been the affirmation by many courts of the right to treatment or education of handicapped persons (Alabama and Pennsylvania especially). Some of these court decisions have been directed to single institutions around single individuals, while others have been the result of class action suits against entire agencies requiring them to show that they are producing adequate treatment or education for all handicapped persons for whom they are responsible. Most of these decisions have required evidence of a specific plan of services (treatment or education) for each handicapped person. In addition, some courts have spelled out staffing ratios and certain operating procedures that must be demonstrated as evidence of adequate service. Persons are no longer to be held in institutions without evidence that such treatment plans are being implemented.

Aside from the skills for responding to class action law suits of this kind, these trends require skills in developing and implementing treatment plans for individuals. Now we must have the skills for planning individualized programs with time schedules and with outcomes that can be monitored to assure that the plans are being implemented. No longer is it sufficient to have only general care for all handicapped residents in institutional programs or simply to include retarded youngsters in the regular public school programs. New planning, record keeping systems, and monitoring skills must be developed to meet these demands.

Another aspect of the Human Rights movement is the reaffirmation of the right of the handicapped to privacy, personal dignity and a better quality of life—especially in institutions. We can no longer tolerate gang bathrooms, censorship of residents' mail, drab uniform-like clothing, and regimented daily living schedules. Program leaders must be able to articulate the elements that make up a higher quality of life; they must also establish procedures to assure that these elements are present despite limitations of resources.

COMMUNITY BASED PROGRAMS

Closely related to the "right to treatment" decisions is a new movement to locate programs for the handicapped in the communities. Despite the fact that there is an increasing number of severely and multiply handicapped persons surviving past infancy, there is a trend to halt the development of any further institutional facilities and a concomitant effort to encourage and assist communities to provide a wide range of services so that the handicapped may remain in their own homes and communities and live as normal a life as possible. There has been a great acceptance of the concept of helping the person with some residual disability to function at his best possible level at home. Schools, businesses, industries, churches, and social organizations are much more willing to serve the handicapped who just a few years ago were excluded because they "were of below average intelligence" or "not fully ambulatory."

These trends require a wide range of new competencies for the agencies and professions that work primarily with the handicapped. They are learning to work with lay groups, community agencies and the public at large. This requires community planning skills, consultation skills and educational skills—the skills directed to helping the staff persons of various agencies to know how to work with the handicapped in their regular programs and the ability to help the general public to understand and accept the handicapped in the community. It requires skills in community development and advocacy to get new resources, facilities, and services for the handicapped in the community and to change rules, regulations, and policies that formerly blocked the developmentally disabled. It also requires skills in the use of the media, in working with the political and civic leadership of the community, in using consumer groups, and in working with courts and other parts of the community with which we have customarily had little to do.

Furthermore, as services move to the community level, we see the amalgamation of a variety of public and voluntary agencies linked in providing services for the handicapped. This requires a variety of interagency contracts and agreements for funds, services, and records. The overall program administrator must have the skills to develop and monitor these purchase-of-service contracts and agreements. It is no longer sufficient for him to be concerned only with the legal and financial aspects of his own program. For the voluntary agency there must be new skills of contracting for certain services and assuring that those services are delivered and linked according to the terms of the contract. This kind of accountability to an overall program administrator has not been characteristic of most voluntary agencies.

MANAGING MORAL DILEMMAS

The presence of larger numbers of severely and multiply-handicapped persons in our society requires even greater development of highly sophisticated professional skills for working with these persons. In fact, our technology's fabulous success in maintaining life in some of the very severely disabled persons has raised serious moral dilemmas about whether we *should* apply these technologies to maintain life at all costs. While this kind of moral dilemma is not unique to the developmentally disabled, it does have specific import for workers in this field. This requires deftness in working with families of the disabled and with staff persons when these issues arise. The issues are legal, moral, religious, cultural and psychological. Closely allied is the need for genetic counseling–skills which have generally been reserved to only a few specialists, but which now are being expected of more and more workers.

UMBRELLA HUMAN RESOURCES PROGRAMMING

These new concepts and trends in *services* require new trends in *programming and administration,* and we find that another host of new skills is necessary. Perhaps the most overwhelming problem here is the movement to plan and program a wide range of public human services programs together at both the state and local levels. Until very recently most human service programs were planned and structured according to narrow categorical programs–mental health, mental retardation, crippled children, tuberculosis, etc. While there are some exceptions, there is now a trend to plan, finance, and structure public programs under much broader groupings. The concept of the developmental disabilities is one manifestation of that trend. However, with the Allied Services Act before the U.S. Congress and with new Departments of Human Resources or similar composite agencies in nearly half of the states, there is an even stronger need to incorporate developmental disabilities within a broad human services framework that includes health, rehabilitation, welfare, and corrections as well as mental health, alcoholism, drug abuse, and aging. At the same time, there is a drive to locate the initiative for statewide planning and development of programs at the state level–in commissions and councils as well as in the state departments. This is somewhat different from the usual establishment of a state plan to which local proposals must conform. Rather, it requires an active reaching out to help local communities to develop and carry out their plans and programs. In addition, there is a strong expectation that both state and local planning and programming will include substantial consumer involvement.

HUMAN RESOURCES PLANNING

These trends require many new skills. Chief among them are skills for planning, but especially in relating to a broad range of human service agencies, local governments, citizen groups, voluntary agencies, consumers and funding sources. More precisely, we must develop skills of advocacy in the broadest sense of encouraging these agencies and groups to get together and initiate planning and programming on behalf of the handicapped. But we must also have the broader skills and knowledge to participate in planning and programming for other areas of the human services for which we have not traditionally had much concern—the poor, the aged, the offender, etc.

CONSUMER INVOLVEMENT

We need also to develop sensitivity and ability to work with consumers and citizen groups—especially those from minorities—so that we truly encourage their contributions and participation in planning and operating services. Professionals and administrators have traditionally been the experts who "knew it all," and who prescribed and gave orders for clients, but most of them have had no training for the role of eliciting and allowing consumer participation in defining problems and setting plans. This is the age of the consumer, and these skills must be learned by the professionals who will work in programs for the handicapped so that consumer participation works at more than the token level.

MANAGEMENT BY OBJECTIVES

At a more specific level of program planning and administration, we find several new trends. One of these is the trend to some kind of "management by objectives." There are many approaches—Program Budgeting, Program Financial Planning, Key Factor Analysis—but all have in common the notion of spelling out some kind of program objectives to be accomplished with the corresponding budget costs. Most public agencies are moving strongly away from the traditional lump sum or line item budgets to some form of program budget. Administrators and staff must learn the techniques of developing and executing a program budget. In the most sophisticated of these techniques, the objectives must be stated in measurable terms of *outcomes* to be attained for the clients—not in terms of services provided. This is often extremely difficult to do in the human services and especially for the handicapped. It is particularly difficult for most professionals who are accustomed to thinking and being paid in terms of the services they provide rather than in terms of outcomes attained by their clients. These new management techniques focus on cost effectiveness rather than on professional perfection. This often requires professionals to think more in terms of offering consultation and education to family members and to lesser trained workers rather than spending all of their time in direct client services. The administrator will also need to be able to persuade the professionals to make these changes in their roles and methods.

MANAGEMENT INFORMATION SYSTEMS

Closely related to these new forms of management by objectives is the matter of newly developing Management Information Systems. The record keeping and data systems in most human service programs, and especially those for the handicapped, have been almost useless. They have given us little more than just gross totals of the numbers of persons served with only the crudest data about the individuals or of the services, costs, results, etc. Sophisticated record and data systems closely related to objectives are being developed in many places. Most are computerized and require a fair degree of technical skill, especially in their use for management and evaluation purposes. Selecting key management information items and the analysis, correlation, and interpretation of all of these data will require sophisticated skills on the part of program planners and managers. Skills of data management for program evaluation and administration are almost universally excluded from the professional training of all workers in the human services today.

NEW MANPOWER TRENDS

New Levels of Workers

Besides the important functions of data management and budgeting, the other major function of administration is deployment and use of human resources–the personnel function. In the area of manpower there are several new trends. One of these is the development and use of new levels of workers in the human services.

In institutions we traditionally have employed only a few full professionals and a large number of aides or attendants who had no formal training for their work nor any status in the system. Now we are developing a more coordinated manpower system for the human services, including: (1) New Careerists, (2) technical level workers with certificates or associate of arts degrees from two-year colleges, (3) associate level workers with bachelor's degrees as well as (4) the professionals. Community programs as well as institutions are beginning to train and use these workers. Some programs have been very successful while others have failed badly in introducing and using new workers.

The Generalist Human Services Worker

In some places the new workers are used only as aides or assistants to the professionals, or they are given only limited or menial tasks and responsibilities. Some places have well-developed career ladders for these workers; others have only dead end jobs. Many of the more successful programs are training and using the new workers as "human service generalists." These workers are assigned to work with a small group of clients and their families to get to know them and to help them in the *totality* of their problem–whether the needs are medical, educational, financial, occupational or whatever. The worker plays whatever roles he can to help his client; he calls on consultation from specialists in the various agencies when he needs it, and he refers to specialists when it is required. But even then he retains a close contact and relationship with the client which enables the client and family to feel that they have a personal agent working on their behalf in the maze of agencies and professions, to listen to their problems and to represent their special concerns in the overall planning. This is often the best way to deliver the professional expertise of the various specialists rather than having each specialist spend his limited professional time with the client in somewhat disjointed one-to-one sessions in the usual professional pattern.

All of this use of new levels and kinds of human service workers will require skills in staff supervision, communication and consultation of new or improved kinds. In addition, administrators will need special skills for introducing these new manpower patterns into their programs.

STAFF DEVELOPMENT

Another major need of administration in the area of personnel is the whole matter of staff development. The newer skills and techniques that have been listed above must be taught to professionals and other workers. Continuing education programs must be developed to sharpen and update the skills of existing staff. New workers will have to be trained (sometimes in inservice education programs) for their jobs. Others will require orientation to new program directions and agency procedures.

The skills of planning and carrying out continuing education for technical competence in clinical work are complex enough, but they are only a part of the needed staff development skills. Perhaps far more important are the skills that must be developed for overall program planning and administration. Most organization experts feel that the autocratic managerial style in which everything is decided and handed down from the top is not the most appropriate style for the human services. Rather some form of participative planning, program development, and management is more likely to meet human needs. However, very few human service professionals have the training to be able to lead or function effectively in this kind of organization. In fact, there are even subtle biases in many of our professional schools against selecting persons into basic professional education who might have inclinations to use participative management styles. Thus a major skill in staff development which will be required of every level of manager is that of organization development–helping all levels of administrators and supervisors to be able to participate in setting objectives and priorities, planning goals and programs, coordinating efforts and reshaping programs based on sound data about their effectiveness. Then we shall have true management teams with participative management.

Several universities offer courses in administration that cover mainly the mechanics of administration (budgets, inventories, personnel procedures, etc.) and ignore some of the more important aspects such as setting policy, defining the philosophy and objectives of the organization, personal styles of leadership and bringing about changes in organizations. To some extent the expertise for many of these broader aspects of administration is gained in the field rather than in the university. Perhaps there should be a much closer tie between the universities and the field for training in administration–especially in staff development for persons already in leadership positions in the agencies.

The newer trends in services and administration of programs for the handicapped have been discussed, and some of the new skills needed to meet these trends have been identified.

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Developing Cooperative Efforts Among Public and Private Agencies

Rolf R. Williams

The subject under discussion is probably the very root of the whole new planning mechanism created by the Developmental Disability Act (DDA). It is a further continuation of the interrelationship that has been occurring during the past 15 years between public and private agencies serving and planning for the handicapped. It is vital that we begin to clarify these relationships and look at them in the light of the period in which we are living.

During the past ten years we have been working in very foggy areas in these relationships and have participated in what I refer to as "personal diplomacy." Personal diplomacy is one in which a particular personality from a voluntary agency, usually on the local level, creates a relationship with a public agency to further advance funding for programs which the voluntary agency is operating. This created a situation where we found good cooperation between certain voluntary and public agencies in one community and programs supported by a combination of public and private funds in that community. It is impossible to duplicate the same situation in another community due to personalities and variations in the public and private agencies. This type of diplomacy can no longer be tolerated. Both the public and private agencies will have to have a thorough understanding of their own goals, policies, direction and funding. They will have to develop the same understanding regarding all of the agencies in the community which make up the total service system for the handicapped.

In this light I would like to go into some specific methods and philosophies in which this cooperation can occur. Due to my background and particular interest I will focus mainly on the responsibilities of the voluntary health agencies on the local level. However, the concepts will hold true to a great extent for the public agencies and state and federal levels as well.

The private agency must have a thorough knowledge of what role and direction it will play in the community. It will have to emphasize one of three distinct roles and clarify its policies in each role as they relate to public agencies. The roles are different and they require different types of relationships with the public agency.

PROVIDERS OF SERVICES

In this country the most popular role of the private agencies involved in the DDA mechanism would be the role of provider of direct services to a specific clientele. These services can be workshops, day care centers, rehabilitation centers, diagnostic centers, etc. These services place the voluntary organization in the role of a vendor or contractor to a public agency in most cases. As such, they are under the mandates of the agency to which they are selling services. The agency could be a department of vocational rehabilitation, regional MR center, social welfare department, public school, or others. In this role they have an ancillary position to the public agency to which they are providing service. In this role they are particularly obligated to know the function and the purpose of the public agency with which they are working and be forthright in the information they supply the agency, the result of the program and the request for ongoing growth and expansion of the service. They must be aware of the changing nature of the public agencies. They cannot expect one public agency to meet every need of a particular developmentally disabled population. For instance, day programs for adults cannot be provided only by Vocational Rehabilitation but must involve Adult Education, Social Welfare, and Park and Recreation Departments. Much criticism of DVR in the past has come because this agency dedicated to vocational training was expected to involve itself with a non-vocationally oriented population. We all have muddied the water in the past by forcing particular agencies into providing services, into buying services, or into supporting services which they were not legally nor philosophically equipped to handle. Remember, I am speaking of the voluntary agency playing the role as a provider of services at this point.

ADVOCACY ROLE

The voluntary agency may take the primary role of an advocate or a catalyst in the community. As such, they will not be selling services to a public agency and in such a role the situation becomes almost the opposite of the previous role. They will have an obligation to criticize, to investigate, and to initiate changes in the public agency. They will also take on the obligation of looking at the programs which are supported by the public agency. They will also look at the philosophy and legal foundation of the public agency and work for changes in them. They will be constructive in their criticisms but will not be in a position to be fearful that someone might disagree with their criticism of the agency and cut off their funds. This is a very dynamic role and one in which the National Association for Retarded Children, United Cerebral Palsy, and others have claimed as a part of the national, state, and local policies but have not really taken it on as a dynamic challenge at this point. I think the change in support of programs to more of a tax supported system of services will demand that more voluntary agencies take on this role than has been the case in the past. However, this will require a great deal of change of thinking on the part of the voluntary agencies in the way they view their own roles, the way they sell themselves in the community, in the staffing, and in their entire purpose of being.

TRANSITIONAL ROLE

The third type of voluntary organization is one which I will refer to as a transitional type. This will be the type which most groups will become during the next few years. It will allow them to maintain their image as providers of direct services in their communities and will also gradually make them more viable in the advocacy role and in total community planning. This will be a very trying period for all voluntary and public agencies in that the switching of roles will be very traumatic on both sides. It is likely to lead to confusion, hard feelings, changing bases of support, changing leadership, and other factors. The private agency will take on direct services only as a demonstration project with a definite goal and plan for the absorption of the program by the public agency. The private agency will possibly supply funding and the local share of grants for public agencies to enter a new program area. It will insist that when this is done, staff and volunteers must be in a policy-making position as it relates to the program they are funding.

The voluntary agency is going to see the growth of permanent public services to the handicapped. They will have to begin to insist on permanent funding and much less reliance upon grants for demonstration programs. I feel in the transitional phase this will occur very rapidly.

Volunteers and staff of all voluntary health agencies concerned for the handicapped must in the next year discuss the type of agency they want to be and clarify in their own minds their philosophies and long-range goals in relation to these three roles. At that time they must begin to communicate to the public agencies and other private agencies what role they intend to play in the development of services in their community. They can receive help in determining this role from other agencies, through coordinating councils, through personal contacts and through a study of the developing service systems in the area. Through this process they will gain more understanding from sister agencies both public and private and build better relationships. I must state here that goals should never be so solidified that they cannot be changed with the times. Only through this basic understanding and coordination can agencies, both public and private, begin to relate to each other in a trusting straightforward manner. Unless this basic role is understood, there will always be the worry of hidden agenda when the private agency speaks. We cannot eliminate this factor but we can begin to modify it.

There are certain factors that all private agencies must understand as they enter agreements or relations with public agencies no matter which of the three roles they take on.

They must understand the legal, political and philosophical base of the public agency with which they are working. This includes the influence of federal, state and local legislation, as well as administrative policy, philosophy and internal conflicts that go on within the agency. By internal conflicts I do not mean personality conflicts but legitimate swings in basic philosophy of which we are apt to be seeing more of in the future. For example, what will the change in the Vocational Rehabilitation Act mean to the philosophy of the line worker in your local vocational rehabilitation agency? A voluntary agency planning to use the new Vocational Rehabilitation Act verbiage must understand this factor.

The voluntary agencies traditionally have not been involved in long-range budgeting or planning. Most of them budget and plan for a year at the most. In the developing interrelationship between public and private agencies, the private agency will have to understand the budgeting processes of public agencies which range from 18 months or 2 years to as much as 5 years in some cases. This means that input from a voluntary agency, whether it be program or budget, to the tax supported agency will have to occur long before the effective date or the fiscal year. This is the only way that the consumer input can be effective, whether it be as an advocate agency or as an organization providing direct services to the handicapped and the public agency. It will be one of the most difficult items for us as Developmental Disability Council members and others involved in any DDA mechanism to get used to. Planning will have to be done two to three years in advance. Most of us are so used to putting out day-to-day fires that it is difficult to look that far ahead.

Long-range planning also implies that we might well refuse certain money for momentary gain. We as planners must not use money for programs until our planning is advanced enough to give us good priorities for spending just money. For instance, construction money and DDA grant money spent too early could perhaps continue a system of services that is already twenty-five years out-of-date. In such a case we might do well not to spend the money until we can find a new system of services that is more applicable to the community and current thinking.

With the changing relationship between public and private agencies, it will become more and more vital that the public agencies, whether on a national, state, or local level, provide their members with up-to-date, correct information as to how legislative and administrative policies will affect the legal-financial status of all public agencies. It is very frustrating to work with a local United Cerebral Palsy affiliate that has heard that something could be done under the Social Rehabilitation Service Title XVI funding in another state or county, but it is illegal or against regulations or policy in their state or county. They may accuse a local welfare chief of dragging his feet when it is completely out of his hands. I feel this factor should have more influence on the way we as voluntary agencies distribute information from national and state offices. This requires that we must develop volunteers and staff with a great deal more technical knowledge of government and public agencies' procedures.

Related to this has been our almost complete failure to give constructive input into the development of guidelines and policies to implement new legislation on all levels. We have strenuously worked to have certain legislation passed, but we have forgotten about it during the period of developing guidelines and administrative procedure and have ended up with the opposite effect than that for which we worked.

Voluntary agencies in the new partnership will have to become more aware of their relationships with other such agencies on the community, state and national level. If this awareness is reached, it will bring about cooperation in services, legislative activities, public education and other areas which will provide better services to the handicapped. However, everyone working in these agencies is aware of the underlying need to certify the existence of their agency to the public and to the government. I am sure all of the voluntary agencies have a very important role to play and will be more vital in the future with the demands of such acts as Developmental Disabilities. The voluntary agency always has and must continue to be the leader in new dynamic programs and philosophies. However, we must talk about the financial support, the public image, and the role of the voluntary agency. We must talk about the basic structure as a voluntary agency in a factual way and not keep burying it under cliches. We need to develop true cooperation with other voluntary agencies in the field through complete self-understanding. This cooperation often is stymied at a very delicate point because we have neglected to discuss some of the basic needs of the organization.

We need to clarify the functions of various members of our local voluntary agency as to what roles they play. Here I am speaking of the roles of the volunteer and the staff that might be played in the new relationship between public and private agencies. What is the legitimate role of the paid staff and what is the functional role of the volunteer? At this point I am not simply talking about policy versus administration but rather I am speaking of the active role of each in this new relationship. It has always been my basic philosophy that staff should primarily work with staff of other agencies and be concerned with planning or the implementation of plans. The staff should be the backup to the volunteers. They should limit their committee work to staffing committees and interagency staff committees and task forces. The volunteer, board member, etc., should be encouraged and trained to participate as an informed community or consumer representative on boards, committees, task forces or other bodies. He should mainly relate to other volunteers taking leadership roles in the development of community programs. He should be the spokesman in front of elected officials such as school boards, legislative committees, boards of county commissions, etc. In this role he should have the backup knowledge of the staff members and his agency and rely on them for more detailed information and for follow-up work on the staff level as they work with the staff of the public agency. The timing and judicious use of these two elements (staff and volunteers) in the voluntary agency can be the most effective tool we have in creating true cooperation between agencies.

The new relationship between public and private agencies will require a much more sophisticated professional working for the private agencies. He must be able to relate to his counterpart in the public agencies in a professional manner. He must have a full knowledge of his agency's goals, purposes, reason for being, and must be a technical expert in developing his agency's relationship with public agencies. He must be a neutral resource to the public agency with information relating to the particular diagnostic category his agency is dedicated to. For example, if he is an executive of an Associated for Retarded Children unit, he must be informed of the entire problem of mental retardation and be a community resource for mental retardation. He must not limit himself to just knowledge of vocational rehabilitation and mental retardation simply because his unit operates a workshop. He must be viewed by the public agency as a trustworthy person with whom they can share confidences and look for help in situations where they are stymied by agency policies or agency communication problems. I have found many times that a director of special education or some other public agency has come to me with a problem and states "I cannot do anything administratively but your group as a private agency could help out." In this case it is our obligation to verify the information, to build the facts without using the source and then bring it to the attention of the private agency's policy-making board and pursue it through higher levels of the public agency. In this way we are able to use our consumer clout to help out staff in a public agency setting. This is a very good way to build up good positive staff working relationships. However, the voluntary agency should never allow themselves to become a part of the bureaucratic or political game. We can only harm our position in the community by doing this and also become very confused in our own role and goals.

CONCLUSION

I would like to make the point that in the next few years we are going to see a very dramatic and traumatic changing of roles, shifting of roles, shifting of legislative bases, shifting of attitudes in the voluntary agencies, and changing of the whole role of voluntary-ism in America. If we are to see growth and development in services for the handicapped on a meaningful community, state, and national level, both the voluntary and the public agencies will have to keep pace with these changes. Each one will have to develop new strengths and new roles. Each one will have to release some of its former responsibilities. This job will not be easy to do, but we must make a start now as individuals concerned with the developmentally disabled, whether we represent public or private agencies on local, regional, state or national levels. We must first understand our own agencies and goals and then understand other agencies if we are to succeed in this tremendous task.

WORKSHOP DISCUSSION

The following is a review of certain factors that were brought out at the DDA conference workshop in which the foregoing paper was presented. These comments are being added to the paper in the hope that it will provoke thinking in the area.

The major comments regarding the paper could be divided into two distinct areas. One is the nature of the voluntary agencies involved in DDA planning, and the other is the future role of these agencies advocates. These two points will be treated separately.

Several times during the workshop it was pointed out that the voluntary agencies involved in DDA are parent groups. They have a background and makeup that has placed them in the direct service role. Their basic strengths lie in the participation of parents who needed a service for their own child. What the paper is implying is a change in the traditional role which will be very difficult to sustain without destroying the basic forces which caused these groups to be so dynamic during the past 20 years. Thus, it was felt that the role in direct services will need to continue, but there was general acceptance that direct services could be more of the demonstration and exemplary program type if they continue basic direct services such as education and others. It was hoped by many that the agencies such as NARC, UCP and the Epilepsy Foundation would retain their parent input and not become like many of the other health agencies which have mainly staff with a community board of well-known individuals mainly for fund raising purposes. This concept I support but I do have some doubt about whether we can maintain the organizations such as we have known them in the past.

The Advocacy role was seen by many as a rather passive noncommittal role which would involve only a few professional staff. The writer feels that this may be due to a lack of knowledge regarding the advocacy roles and a general lack of knowledge in our overall membership. The voluntary agency has to know how to be a true advocate and know what parameters may be involved. Several suggestions were brought forth in the conversation in the workshop regarding this topic. State and national units of our private agencies may have to begin to provide expertise in training boards and volunteers in community organization, community planning, the advocacy role, funding without direct services, and other areas in which we have very little expertise on the local level. This in turn would encourage these agencies to hire professional staff with talent that would aid them in the move to the new role. It may be that for an executive director they would look for a professional community organization specialist or a community planner rather than a man with a traditional fund raising or direct program background.

Regarding advocacy roles, it was emphasized that one of the first times a voluntary agency took the advocacy role on a large scale and won some ground was during a Pennsylvania law suit regarding the right to education. It was further pointed out that with the suit, even if they won the case, the problem would not be solved. There would be a great need for advocacy to see that the schools and state follow the suit and provide this quality programing.

Of great interest to me was the concept brought out by one reactor who represented the Department of Vocational Rehabilitation. He pointed out that departments such as his department, welfare and education all have their own advocacy roles to help the clients get services from other departments and public agencies to fill the gaps they cannot legally provide. This would indicate that the voluntary agencies would have the help of a public agency in one area, yet they might be criticizing that agency in another area. This is a very important fact to remember that both public and private agencies may have different attitudes and philosophies in different situations, so we must not look at any agency as "all good" or "all bad."

Another very interesting point was made: If a private agency does become active in public education and in creating public awareness, it then gains the entire community as co-advocates and will have support of the general population when it comes to improving services and programs to the handicapped population with which it is concerned. It's when the public in general becomes concerned that we can expect truly dynamic movements in services for the DDA population.

Part IX
State Advisory Councils

Editor's Notes

Any new organizational entity—be it public or private—faces a whole series of problems in defining its role and functions, its internal and external relationships and its operating procedures and policies. State advisory councils for the developmentally disabled are no exception.

The membership of each council was selected by the Governors of the respective states under general guidelines set down in P.L. 91-517. Despite the wide variation in size and makeup of individual state councils, each shared a common set of problems including: (1) how to resolve the internal differences in perspective and outlook among the membership; (2) how to have a meaningful impact on the policies and practices of well established service delivery systems—both public and private; (3) how to establish and maintain a viable working relationship with other state agencies responsible for delivering services to the developmentally disabled; (4) how to organize itself to carry out its mission; (5) how to determine service priority, utilize its limited grant resources for maximum effect and evaluate the impact of its efforts.

George H. Bown analyzes the problems inherent in organizing state DDSA councils from his perspective as a council chairman. He points to the notable absence of directions on council organization in P.L. 91-517 and subsequent federal regulations and guidelines concluding that this omission is wise given the impossibility of developing a blueprint which would fit the peculiar social, political and historical consideration in all 56 jurisdictions. He sees the need for the state council to function as a true policy making body but warns that existing state agencies may be threatened by such a development and attempt to turn the council into just another advisory body. Bown argues in favor of a clear legal mandate for the council (either by state law or executive order). He also discusses the variety of vested interests that are represented on the council including the three major consumer organizational systems, the state bureaucracy, the agency to which the council is administratively assigned, and consumer representatives.

One of the major operational questions which immediately faced many state DDSA councils was: How do you distribute the state's DDSA allotment among the various competing interests in an equitable and effective manner. Gilbert L. Woodside attempts to respond to part of this question in his paper concerning the grant review process. He suggests that the widely acclaimed peer review system established by the National Institutes of Health may offer some guidance for state DDSA councils. After describing the NIH system, the author discusses several built-in conflicts of interest in DDSA council decision making. He proceeds to suggest several strategies a state council might follow-adapted from the NIH project review system–in order to avoid conflicts of interest and provide an effective grant review process.

Organization of State Advisory Councils

George H. Bown

INTRODUCTION

Noticeably absent in the Developmental Disabilities Services and Facilities Construction Act is specific direction in the organization of State Developmental Disabilities Planning and Advisory Councils. This is also true of the subsequent regulations and guidelines emanating from the federal government. In spite of some of the frustrations encountered in attempting to make a Council functional without such specific direction, there would seem to be considerable wisdom in such an omission.

The wisdom of an omission such as this becomes immediately apparent if anyone attempts to evolve a blueprint that could be followed exactly by every jurisdiction identified in the Act and regulations by the word "state." In theory, for example, as Chairman of a State Council, the easiest thing for me to do in attempting to write a background paper on the "Organization of State Advisory Councils" would be to take the organization of the Council that I represent and present it to you as the ideal model. Upon reflection, however, the uniqueness of the Commonwealth of Massachusetts begins to creep into almost every aspect of the organizational construct. We have had a number of years of experience with a coordinative bureau located in the Governor's office which was tailor made to undertake the administrative and staff functions of the Act. This Bureau, which was formerly the Bureau of Mental Retardation, had a reasonably large staff uniquely endowed with exceptional planning skills and who had had the same extraordinary leadership for all of the years of its existence. By simply a name change to the Bureau of Developmental Disabilities, Massachusetts was immediately prepared to begin the business of implementing the Act. Since the old Bureau of Mental Retardation had an interdepartmental advisory committee, we had only to add consumers and representatives from the local service delivery systems in order to have an acceptable ad hoc council. The adequacy of this Ad Hoc Developmental Disabilities Council, in turn, permitted us to provide an organizational base for the permanent Council, far ahead of most states. Having this running start and because of the unique set of circumstances surrounding the initial implementation of the Act in Massachusetts, I have every reason to believe the organizational system set up in the Commonwealth of Massachusetts to be enough different from all other states to suggest that it could not be considered a typical state. I would also believe that the circumstances around the development of each Council in each other state are unique enough to make them also nontypical.

This paper, then, will not attempt to spell out concrete suggestions for how a Council should be organized. It will instead be developed on the assumption that State Councils, as with any entity within a social system, are subject to forces which shape and mold their internal organization, external relationships, operational methodologies, and certainly their effectiveness. This paper presumes that although these forces are in the main generic and universal, the extent of influence and impact they have on each separate jurisdiction is highly individualized and upon being individualized can be utilized by the states to modify their existing organizational structure.

We will look at historical influences, legal influences, political influences, influences of vested interest and influences of consumerism. These are not intended to be an all inclusive recitation of the forces shaping and molding the Planning and Advisory Councils for the Developmentally Disabled. This interpolation of forces into organizational strategy for State Developmental Disabilities Councils will hopefully become the basis for discussion in this section of the conference.

HISTORICAL INFLUENCES

Historically the bureaucratic system has become enamoured, at increasing rates, with all sorts of advisory councils and particularly those involving consumers. They have, however, primarily seen such Councils as advisory bodies and not policy bodies. Under these circumstances, Councils become a problem to the bureaucracy as well as to the individuals the Councils are intended to serve. The problems arise for both—not only because of the increasing numbers of Councils—but also because the Councils have begun to clamor for a policy role. The proliferation of advisory councils and their insistence on a policy voice has led many state governments and now the federal government to begin to reduce the number, delimit their terms severely, and in many cases abolish them altogether. The seeming paradox of government encouraging increased citizen participation while at the same time seeming to challenge the existence of advisory councils cannot help but raise questions in the minds of persons considering membership on any Council, including the State Developmental Disabilities Council. Many of these people also have had experience on other Councils and still have the taste of nonaccomplishment brought about by the "window dressing" definition of their role and function.[1] There cannot help but be questions raised as to what effect any new council might have on the destiny of the population at risk.

As a rather interesting aside, and in keeping with the rise and fall in favor of councils in general, is the most habitual presumption that the State Developmental Disabilities Council is an "advisory council" rather than a *planning* and *advisory* Council. It should be noted, however, that although this diminished role has been accepted in far too many quarters, particularly within the state government, it does not seem to have been intended by the Congress. It would seem the intention of the Congress was that the Council should, in fact, be a planning and advisory council since all references to the State Council in the Act use both words, "planning" and "advisory." Parallel to the question about effectiveness or lack of effectiveness of councils in the past is the increasing suspicion with which both state governments and proposed recipients look at any new federally energized program. Without belaboring the point, there would seem to be some justification of this suspicion in view of the number of programs that have been introduced to states with great fanfare but with less than an optimum level of long range continuity.

Still another historical influence to be reckoned with is due to the fact that existing councils have equal or sometimes even broader mandates within the states for some or all of the programs for the same population. Very often these other existing state Councils have far more definitive mandates and in many cases also have larger amounts of money and/or influence to maintain their viability independent of a State Developmental Disabilities Council. This is particularly true of those Mental Retardation Councils brought into being as a result of the zeal so much in evidence during the early 1960's.

LEGAL INFLUENCES

Each state, in order to have access to the funds available under the Developmental Disabilities Act, has had to establish a state Council and submit a plan. Depending on the state, this is undertaken either through an act of the legislature or through an executive order. The extent of authority given to the Council does not seem to be dependent upon whether it was an act of the legislature or an executive order. It is, however, crucial to the organization of the state Council as to the degree to which the language of the authorization is restrictive. For example, in a large western state the language of the assembly bill authorizing the establishment of the Developmental Disabilities Council is very careful to use the words "shall advise" when referring to any functions of the State Developmental Disabilities Council. This advice giving restriction even extends to the development of a state plan, not by the Council for submission to the federal government, but development for the submission to the state's own Secretary of Human Relations. The presumption being, then, that the plan is a plan for the state government and not of the Council. Further, this state's legislation is even careful to insert the phrase "to the extent feasible" in the section that relates to

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[1] **Advice by a government official to an advisory board regarding their "proper role and function." "members . . . 'need not feel they have to do something or not do something . . but (to use) the tenure of their office to become well-informed; to educate themselves . . . to listen to what the professionals are thinking about.' "**

the responsibility of the Departments of State Government to cooperate with the state Council.

In direct contrast to the tone of the above legislation is the executive order of the governor of a populous eastern state. This order establishes concrete responsibilities to the State Developmental Disabilities Council and allows them reasonably autonomous operational opportunities. These opportunities include reporting directly to the Secretary of Health, Education and Welfare as is implied in the Developmental Act and its regulations. The tone of this Executive Order is best exemplified by the following quote, "Council shall be entitled to call upon any department, agency, or office of the State of ________ for such documents, materials, and information as it may deem necessary, and shall be entitled to the cooperation of every department, agency, and office of the State of ________."

Another one of the legal influences that one must address in attempting to look at the organization of state councils is the legal mandate of agencies or councils which deal directly or indirectly with the developmentally disabled and are currently in existence. Although the Developmental Disabilities Act calls for the Developmental Disabilities State Councils to undertake certain behaviors and implies certain mandates in working with other councils within the state, the mandate does not take into account the legal responsibilities of the existing agencies or councils. We cannot ignore the fact that fiscal accountability as alluded to within the Act belongs solely to the state government, except in the unique circumstances which have established State Planning and Advisory Councils as a separate legal entity. Therefore, Council members must recognize that state governments have a specific legal responsibility with regard to the expenditure of money no matter how their review committees are set up or what they think they are going to do with the expenditure of money. A consequence of such conflicting legal authorization may well provide a material interference in the functioning of the Council itself.

POLITICAL INFLUENCES

To deny the reality of having the state Councils operate within a political environment is pure folly. The Councils are appointed by the governor and in almost all cases have their tenure controlled by the governor. The overtones of such a relationship were clearly articulated at a recent meeting involving several State Developmental Disabilities Councils and their staff. One participant at the meeting, in discussing the politics related to the Councils, was quick to remind everyone in attendance that given cause, reasonable or otherwise, the Governor would accept their resignation before it was submitted!

Since the State Plan and any subsequent evaluations of the State Plan or of the state program is a reflection on the state government, the possible implications of a negative reflection on the state would have to be interpreted as a negative statement upon the reigning political power. (Need we be reminded that the developmentally disabled are usually not considered to be a powerful voting block?) With this in mind, some fascinating dilemmas can be imagined. For example, if in its role as an advocate, the Council found probable interference with the constitutional rights of the developmentally disabled could they join in a class action suit against the political system of their own state? If they join a class action, it is doubtful that they could remain a politically viable body. On the other hand, if they did not join the class action it is doubtful that they could remain viable as representatives of the developmentally disabled.

INFLUENCES OF VESTED INTEREST

The Developmental Disabilities Act brings together the three major consumer organizational systems that have had for many years a need for individualized recognition. In practice the thrust of their organizational system has been geared, by their own judgements, toward relatively independent behaviors. Even though there has been some coalescence of these divergent activities on a national basis, the probability of immediate ecumenism on a local or individual constituent level seems to be a great deal to ask. In effect, the organizations for the retarded are to give up their preeminence established numerically, organizationally, and fiscally; this seems almost contrary to human nature.

The consumer organizational system is not alone in this conflict of vested interest because the same circumstance can be described for local deliverers of service. Each of the agencies, particularly those under private auspices, have waged a gentle (and sometimes not so gentle) war for a larger proportion of the available resources. The action of bringing these diverse agencies together into one Council would seem to be an extremely small step on the long road toward having them eventually divorce themselves from the competitiveness nurtured by the need of self-perpetuation.

Not to be ignored is the vested interest of the bureaucracy. Bureaucratic representatives on the Council are not only legally obligated toward the maintenance of their own agency, but they are also obligated by virtue of their own needs to insure the continuation of their jobs. Although the question of self-evaluation is risky for the consumer segment of the Council, it would seem even more dangerous to the bureaucratic section of the Council. Also many state agencies have further legal constraints with regard to the manner in which they can evaluate another agency within their own system. Beyond the legal constraints, it would seem difficult to imagine any bureaucratic system functioning without closing of the ranks against those outside the bureaucracy. In effect, if one is attacked, all are attacked—if one is vulnerable, all are vulnerable.

While considering the vested interest of the bureaucracy, it becomes appropriate to raise issues about the placement of the staff of the Council as well as about how the Council is administratively linked to the state government. The problems of evaluation inherent in the Council's placement in an agency whose level in state government is equal to or below other agencies on the Council would seem fairly obvious. Under the circumstances, if the Council must be linked to a state agency, and indeed it must in most states, that linkage should be at a high enough level to command the attention and cooperation of those agencies represented on the Council. This linkage, in any event, should be considered "in but not of" the governmental system and the allegiance of the staff must be to the Council and not to the agency.

INFLUENCES OF "CONSUMERISM"

Although the concept of the "consumer" does not in itself become an independent influence in the organization of Councils, "consumerism" when taken in conjunction with other influences does. There is a self-evident parallel between consumerism and vested interest as described earlier relating to the consumer organizational system. The nature of the development of consumerism has been due to the recurring reality of disappointing service delivery. This would tend to encourage the consumer element of any Council to look toward the Developmental Disabilities Act for immediate gratification of service deficiencies. In effect, this establishes a contradiction to the efficient utilization of monies available to any Council and also to the interstitial nature of the legislation itself. The delicate balance necessary to maintain the consumer on a Council as a viable decision maker has to be maintained by attempting to define a new role for and with the consumer (representative) as a *strategist* rather than a seeker. Consistent with this new role, the consumer is squarely confronted with the various bureaucratic or quasi-bureaucratic systems that have always confused and confounded him in the past. The very nature of the jargon and the sureness of the public and private providers of service in explaining their mission would tend to deny the consumer any comfort as an equal partner in a discussion. In this case, the influence of the consumer becomes a null influence, by omission, that can be rectified only through concerted supportive behaviors toward that consumer.

The same null influence of consumer uneasiness can be carried further by attempting to look at the question of true consumer representation on the Council. Before one looks at the absolute numbers of consumers to be represented on the Council or their assignment to committees or the like, the question as to what is to be expected of the consumer must first be resolved. Does "consumer representation" mean (beyond the definition in the regulations) that he should be truly representative of a majority of consumers and being "representative" be incapable of competing as an equal in the strategies of the planning process? Does it mean that we cannot have mentally retarded individuals or severely physically handicapped individuals on the Council because the ebb and flow of Council decision is beyond their comprehension or the place of meeting is inconvenient for the handicapped? Does it mean that the Council cannot use the input of the heads of marginal income households because the meetings are held during the work day? Beyond the loss of income, do the time and energy demands made of a Council member in preparing for and attending numerous meetings suggest Council consumer membership must be drawn from the "elite"?

The final point to be raised relating to consumer influence is the need for recognition of the fact that sanctions for the organization of State Councils come not only from a political side of state government but also must be obtained from the consumer side of the state. Therefore, not only is the representation question germane to our discussion but also the question of how effective does the consumer feel the Council is or should be. The history of promise and subsequent disappointments weighs heavily on the consumer; and his continuing interest, therefore, becomes extraordinarily tenuous. It does not now take very long for the consumer to recognize the limitations of "consumer influence" and the time for such realization will become even shorter as each promise is held out without fulfillment.

CONCLUSION

As promised in the introduction of this paper, little has been done to offer concrete examples of how a Council should be organized if, in fact, there is an ideal way of organizing Councils. The questions and issues raised would hopefully provide for a sharing of ideas allowing for the Councils represented at this conference to apply their own organizational strategies within the constraints or advantages of their individual States. In conclusion, however, it would seem appropriate to offer some general suggestions directed toward "Organization of State Advisory Councils" which are as follows:

(1) Organizational emphasis of Councils should be placed on planning and not on delivery of services or construction.

(2) Councils should be mainly consumers or possibly totally consumer in their makeup.

(3) State Planning and Advisory Councils should be as independent of the bureaucratic system as possible. A concept of "in but not of" should be built into any organizational system developed.

(4) The State Councils should be affiliated, if affiliation is necessary, to the highest level of authority within the States, preferably the Governor's office.

(5) The Planning and Advisory Council should through its by-laws, membership, and behaviors balance both informed and uninformed consumer representation.

(6) Vested interest representation should give way to interest which embraces the broader concept of the developmentally disabled as opposed to the integrity of a category.

(7) State Council staff selection should be geared to the needs of the Council, be *truly* adequate, and be under the explicit direction of the Council only.

(8) There should be built into Council activities a continuous "in-service" training program for all members of the Council with particular attention to the needs of the consumer representatives.

(9) Inputs to the State Council should be broadened to the fullest extent possible through all possible mechanisms including public hearings, ad hoc membership, and committee appointments.

(10) There should be a continuous flow of public information from the Council regarding activities of the Council to allow for the broadest community response to the Council.

ADDENDUM

The nature of the discussion following the presentation of the paper entitled "Organization of State Advisory Councils" was molded not only by the contents of the paper but also by the diversity of the audience. This diversity, while encouraging interaction, also led the discussion toward individual needs to be heard. A fact also to be considered in review of the discussion is the problems inherent in conflict resolution when full discussion is prohibited by the constraints of time and the need to hear from as many people as possible. The discussion seemed to center around four major areas including national leadership, the question of consumer representation on Councils, staff role and direction, and individual state implementation.

National Leadership

The question of national leadership was brought up directly as a major topic of conversation as well as indirectly on several occasions. One member of the group voiced the opinion that a great deal less confusion would arise over the implementation of the Act if the federal government and its staff were to take a more definitive role in laying out the expectations of and from the individual State Councils. The response to this concern took the form of tracing the evolution of the Act which placed particular emphasis on the concept of states' rights. Inherent in the concept of states' rights was the responsibility for each state to evolve its State Plan and strategies according to the states' particular needs. Guidelines were intended to given general direction rather than specific prescription. The feeling was expressed that while more specific central direction would be helpful in some areas, it would in the long run deprive the States and the Councils of their local autonomy and responsiveness.

Consumer Representation

Considerable discussion was evoked by the suggestion in the paper that heavier emphasis be placed within the Councils on "consumerism"; possibly to the point of having the Councils made up totally of consumers. The pro's and con's of such an approach were discussed with particular interest being expressed on the need for continuing inservice training if we were to have active consumer participation. Support was given to the participant who felt that the intention of the Act was being met by having a mix of State agency representatives and private service delivery representatives, as well as consumers live and work together toward a common goal. The question of true "consumer" was raised as was the question of the evolution of the sophisticated consumer who might overpower the unsophisticated consumer. Inclusion or exclusion of particular types and kinds of representation on the Council were individually defended without any particular consensus except perhaps in the area of reducing vested interest.

Staff Role and Direction

The group found the question of staff role and direction to be a particularly diverse problem although there seemed to be a vast difference between the states in the management of this question. In some states the question, "To whom is the staff responsible?" does not seem to have arisen since the Council Chairman automatically assumed complete responsibility for the direction of staff. Yet, persons from other states expressed frustration in that they felt that they had absolutely no control over selection nor direction of the staff. The feeling was expressed that in these states the person controlling the paycheck controls the employee; and since the administering agency pays the staff, it gives the direction. Some emphasis in the discussion was placed upon that section of the regulations which refers to adequate staffing for the Council, with the implication being that the phrasing of that section of the regulation could and should invest in the Council responsibility for the direction of staff.

Individual State Implementation

Although individual "show and tell" was seemingly avoided by the participants and not encouraged by the Chairman, some time was spent on using particular state activities to demonstrate particular points. Several states used the regionalization concept to reinforce their description of statewide participation and training. It was also felt that coalescence of regional planning activities made for a stronger "grass roots" State Plan which was much more reflective of both consumers and generalized State needs.

Another reference to coalition was coupled with the need to reduce vested interest by the various consumer groups. It was suggested that by joining forces the various consumer factors might efficiently direct their energies toward mutually supportive behaviors such as legislative change.

One additional area was clarified both through interpretation and discussion. In the presentation of the paper there seemed to be the impression conveyed that planning was interpreted to be in opposition to the provision of services. This was not intended and the group found that concept of planning *for* services much more acceptable. They did, however, seem to emphasize the need for a planning strategy rather than having Councils move toward an exclusive service delivery type of activity.

Project Grant Review At the State Level

Gilbert Woodside

The Developmental Disabilities Services and Facilities Construction Act (P.L. 91-517) offers a multipurpose and multifaceted Federal grant-in-aid approach to the strengthening and expansion of services for developmentally disabled persons. The variable grant formula to states can be used for planning, administration, delivery of services, training of personnel, demonstration, and construction of facilities. The diversity of use, while highly advantageous in the scope of activities covered and in the potentially flexible use of allocated funds, poses difficult problems of quality control in project grant review.

NIH PEER REVIEW SYSTEM

The widely acclaimed peer review system of the National Institutes of Health may offer some guidelines in this regard, but the underlying processes and modes of funding are vastly different. Some programs within the NIH such as the now terminated construction grants for Mental Retardation Research Centers, bear striking similarities to the University Affiliated Facilities construction program. In such instances, or in the special projects section of the Developmental Disabilities formula grant programs, the procedures and principles of the NIH review system are clearly applicable. However, the distribution of formula grants through State Planning and Advisory Councils and designated state agencies to a variety of eligible participants, is another matter. Here, priorities, special interests and political pressures may influence the review system and hamper its effectiveness. Because of these differences, each dimension of the problem will be considered independently.

The NIH research program, despite its heavy accent on basic research in the biological and behavioral sciences is nevertheless, a mission-oriented program. Everything we fund must be health-related. The Institutes are charged with finding solutions to specific diseases (arthritis, infection, allergy, cancer) or organ system problems (heart, lungs, eye, dental). More recently established

Institutes have more broadly defined missions, such as child health and human development, and environmental health.

Establishing new Institutes or increasing the budgets of existing ones are two visible ways of setting national priorities. Many factors contribute to this process—concern regarding a major national health problem, the interest of the scientific community, the pressure of consumer groups, Congressional and administration responsiveness. Diverse consequences flow from the commitment of fiscal resources to new program priorities. At the Federal level, expert staff is recruited, peer review groups are formed, and national advisory councils are set up to promote goals and advise on policy. Within universities, departments may assign laboratory space to the new priority and scientists may shift the direction of their research. How extensively scientific interests may shift, or at least appear to, is partly a function of the availability of other sources of grant support. The large number of research faculty supported by Federal funds dictates a survival philosophy by going where the money is, but it also serves the positive function of drawing manpower resources to priority problem solving. This technique, as will be noted later, may be applied in the state's distribution of the formula grant.

At the NIH Institute level of operation, the contract mechanism is one of the primary tools for implementing priorities. Within the regular grant program of a broad research mission, such as child health and human development, the range of possible projects is almost infinite. The Institute must accept what comes to it for review and has little influence over specific directions, except as staff, through consultation and programmatic effort, can encourage certain projects. By contrast, the contract—in the most simplistic terms—is an agreement with an investigator to carry out a research study the Institute wants done. The level of involvement of Institute staff may range from true collaboration to mere supervision of contractual terms, but the important point is that funds can be directed toward specific priorities. These priorities may also be affected by outside concerns, but staff input bears more heavily on the outcome. Another obvious means for stimulating activity in a specific area is through earmarking of funds.

PRIORITY SETTING

The very comprehensiveness of the Developmental Disabilities program and the variety of interest groups it serves, greatly complicate the priority setting task. Competition between groups is inevitable when all must share a common resource pool and when the pool is insufficient to the total need. The requirement that consumers be represented on advisory councils does not guarantee impartiality in priority determinations. Pecking orders are bound to emerge when well organized, politically influential groups such as those concerned with mental retardation and cerebral palsy, are paired with other disability groups. In this alliance, there is the danger that the concept of developmental disabilities may be subordinated to the specific categories subsumed under its umbrella.

The inclusion of state and local agencies and nongovernmental organizations on the State Council further complicates priority setting. The Council is and should be responsible for program direction, development and growth. Since the grant program builds on existing services operated by these agencies, they are clearly the best informed on what is available and what is lacking. Yet, a dilemma exists in that these agencies which contribute to planning and direction are also the beneficiaries of the granting process. In essence, they are advisory to themselves, and the balance of power within the State Council, rather than demonstrating need, may dictate priorities.

Despite the potential conflicts this structure presents, the concept that planning must be a continuous process involving agencies and consumers at all levels is a sound one. The review and approval of State plans by the Secretary through the Regional HEW Office adds an objective dimension to the process, but offers only partial quality control. To properly evaluate such plans for merit calls for a broad range of professional skills, up-to-date knowledge on research, social-legal trends and innovative programs, and delivery system know-how. Few regional offices have sufficient manpower to effectively carry out this role. Furthermore, as staff members for the granting agency, they may be vulnerable to conflicts of interest and subtle political pressures. One possible way of assessing the merit of the state plan and the validity of the priorities identified, is to establish program review groups at the regional level composed of professionals of multidisciplinary backgrounds who are not members of the State Council and a proportion of whom reside outside this region. Members, of course, would be excused from reviewing the plan from their own state. In this way, the review system can be strengthened, made more objective, and by virtue of the "outside experts" bring in fresh ideas.

Modification of Council composition at the state level would also be helpful in avoiding the internecine conflicts that may occur. Professional members from outside the state could become "arbitrators" when necessary and possibly minimize the perpetuation of programs by vested interests of agencies or departments. These suggestions are not foolproof ways of objectifying the planning and priority setting processes, but they should help to externalize the evaluation process and reduce conflicts of interest and political influence. They approximate, in principle at least, the dual review system of the NIH, separating the assessment of program merit (by the program regional review group) from that of planning and policy making (State Council) and adding review personnel outside of the system under review.

The determination of priorities demands in the first instance, of course, a solid factual base of information concerning what kind and how many disabled persons are being served, the nature of services they receive and who provides them, as well as what facilities and resources are available. Client data are rarely available, since few reporting systems designate their clientele by disability categories. Especially is this true for generic agencies to which disabled persons come for reasons other than their disability. Some states have considered using their planning funds to conduct epidemiological studies to assess the prevalence of various types of disability. It would be clearly wasteful for 50 states to replicate one another's efforts. The special projects funds reserved by the Secretary under this Act, may be a better mechanism for this purpose. Sufficiently precise data for planning are already available on urban-rural and social class prevalence and incidence in mental retardation. Through carefully designed studies and sampling procedures, similar data could be obtained on other disabilities. Epidemiological studies of this type clearly satisfy national significance criteria and could provide a reasonable basis for each state to determine need, program direction and distribution of funds.

Other baseline information regarding agency involvement and facilities is already available in many states because of earlier legislation relative to planning and construction of facilities for work in mental retardation. This information needs to be updated and expanded to include other disabilities, and the machinery for its collection is in some states still viable. The data could provide a useful starting point for planning and advisory councils in evaluating the growth and quality of services, program innovations and unmet needs.

At the Federal level, the special projects grants offer excellent opportunities for implementing priorities and developing delivery system models on new services that states could emulate. The National Advisory Council, because of its charge to evaluate the effectiveness of programs on a national level in carrying out the purposes of the legislation, is in a unique position to identify the need for promising and new approaches and where they might be developed, tried and tested. In brief, they could establish priorities and invite grant applications or contract proposals responsive to their interests. The NIH, as noted earlier has used the contract mechanism with considerable success to stimulate research activity in specific areas. Often, it advertises its interests in the Commerce Business Daily and issues a Request for Proposals (RFP) which sets forth in fairly precise terms the aims and scope of the study proposed. Not uncommonly, an RFP generates a flurry of research grant applications as well as contract proposals. It is an excellent way of publicizing the interests of the funding agency.

PROJECT APPLICATION APPROACH

The state plan must satisfy certain requirements of effectiveness in its distribution of funds to states and local agencies. Assurances are also required that some of the funds will be allocated to local groups, that standards will be maintained, records and reports kept, and poverty areas afforded special consideration. The project application approach, as discussed above, can be utilized at the state level as well. Clearly, a major part of Developmental Disabilities funds will be used by the major state agencies for planning, administration and direct delivery of services. The concept of public responsibility for disabled children is well established and in probably all states, the states are the primary providers of service. Nevertheless, there is an important role for the voluntary agency in the areas of family counseling, homemaker services, foster family and group care, adoption and similar services. More important, the voluntary agency can be highly flexible unlike the public agency whose policies and regulations are dictated, and sometimes constrained, by legislative authority. These voluntary agencies have a capacity for experimentation sorely needed in uncharted areas concerning the developmentally disabled. Their resources should be fully exploited.

One way to achieve this goal is to set aside a certain proportion of the state allocation for special project funding–not to be confused with the Federal projects discussed earlier. Here too, the State Council can set priorities and solicit applications through media advertising, contact with professional organizations and societies in the states, and RFP type approaches. At a later point in this application process, the State Council may choose among meritorious projects those proposals which best satisfy priorities and the goals of this State plan.

CONSULTATIVE HELP

Potential grantees under this system may need consultative help in conceptualizing their programs, specifying their technologies and strategies and providing the data for program evaluation. Technical assistance of this kind is likely to be most needed in the least developed service areas of the community. Such help could come from a variety of sources–private consultation, academia, state personnel, or the staff of the granting agency. The important consideration is that individuals involved in the application development process do not review the proposal once it is submitted.

The NIH project review system does not provide a perfect model for state review of Developmental Disabilities proposals, but the underlying rationale is clearly applicable. The philosophy of NIH staff is to support the best research possible and to the extent that preliminary consultation can facilitate this goal, it is freely provided. Where such contact is made with the investigator, he is even invited, if he wants to, to send in a draft proposal for staff review before officially submitting it to the NIH Division of Research Grants. There are self-evident hazards in this process for applications that fail to pass scientific scrutiny, but scientists are aware that consultation, whatever its source, carries no funding guarantees. With few exceptions, they greatly welcome this assistance and there is a fairly positive correlation between staff input and project outcome.

GRANT REVIEW PROCESS

The grant review process is scrupulously separate from the technical assistance to the grantee outlined above. Once the application is formally submitted, it is assigned to a Study Section for primary review. There are many Study Sections, each composed of members expert in a given area of research and selected for their demonstrated competence and esteem in the scientific community. Many of these investigators are NIH grantees. Should their own applications or projects in which they participate be assigned to the Study Section of which they are a member, an ad hoc panel is constituted to avoid conflict of interest. If the applicant is from the same university as the Study Section member, the latter is excused from the review of the project. On site visit teams, geographic considerations are also applied, and consultants are not selected from areas proximal to the applicant. These zealous protections against conflict of interest are the hallmark of the NIH peer review system and an important factor in its success.

When a judgment on scientific merit has been rendered by the primary Study Section, its conclusions and recommendations are presented to the Institute's National Advisory Council for further review. This review includes scientific merit but is concerned primarily with issues of policy, relevance to the Institute mission, and to some extent, program priorities. Council also has the option of questioning the recommendations of the primary group and the adequacy of the review, but this option is judiciously, and thus infrequently, exercised. The recommendations of the Council are advisory to the Director, NIH, except that no grant application can be funded without Council approval.

Some of the proposals are approved and funded, others are approved but cannot be funded, and many are disapproved. In all of these situations, staff contact and responsibility may be reinstated. Funded grants are assigned to staff for management and for evaluation of progress as evidenced through regular reporting procedures. More intensive participation may take place at this time for project renewal. For the grants that are not funded, staff, upon request or by its own initiative, may share with the investigator the critique of his study and otherwise help him to formulate a revised proposal, thus further enhancing the quality of the scientific enterprise.

This capsule version of staff–Study Section–and Council responsibilities indicates the interrelated and complementary nature of the grant review system. While staff is by design not a part of the evaluative process per se, its role in preliminary consultation, administrative management and followup, is obviously essential in carrying out Institute goals. By the same token, scientific review alone, without reference to policy, mission or priorities is less likely to achieve agency objectives.

All of these elements, with modification, would appear applicable to project grant review at the state level. It is economically unfeasible for states to set up an elaborate structure of Study Sections and probably unnecessary to do so. But some kind of primary review mechanism, independent of the designated state agency or Advisory Council, would appear essential. Conflicts of interest are likely to arise when a single body is responsible for planning, program direction and growth, review of projects and evaluating its own state plan. Such potential conflicts would probably be most apparent among consumer members and the state agency beneficiaries of the program. The use of a subcommittee of the Council, supplemented by ad hoc members does not fully satisfy this concern, nor does the review by staff of the administering agency.

It would seem advisable to establish a project grant review group whose members represented different disciplines and various aspects of delivery systems and who were drawn from university settings and public and voluntary agencies at all levels of government. The size of the group should probably not exceed 15 and should rely on ad hoc persons to supplement group expertise. Meetings could be held 2 - 3 times per year depending on workload and should be coordinated with Advisory Council meetings. Financial support for such a group, including site visits where needed, could probably be charged to administrative costs under provisions of the Act.

The independent review system has certain built-in advantages. It protects the Council and administering agency from undue pressures by political and consumer groups and alleviates adverse criticism. It provides for more expert evaluation because members can be selected for their special knowledge and competence. Limited terms of membership could be established. This would help in preventing the development of an entrenched "in group." Many projects will be of fairly long duration; for these, interim short-term review can provide an ongoing mechanism for quality control. Projects that fail to progress satisfactorily could, under this system, be phased out more readily than is possible when activities are both solicited and reviewed by Council or staff. Conflicts of interest, potentially very damaging to programs of this kind, can be greatly minimized.

The Developmental Disabilities legislation offers an unparalleled opportunity to strengthen and extend existing programs and to expand services into new and promising areas on behalf of many groups of heretofore relatively neglected groups of children. To fully exploit this opportunity, however, an administrative structure is needed to insure efficiency of operation, program effectiveness, mission-oriented activity and the assessment and implementation of program priorities.

A system for project grant review, designed to safeguard the quality of the program, is an essential part of this structure. The suggestions outlined above could contribute to this goal.

DISCUSSION OF THE PRECEDING PRESENTATION

Most of the discussion centered about the practicality of the above suggestions, especially in view of the fact that the Developmental Disabilities Program is so new. Concern was expressed over whether in some states there would be enough qualified people to serve on the recommended initial review groups. Some state representatives felt that with the little money available at the present time, it would not be feasible to set up initial review groups which would send recommendations to the State Council. Short deadlines were also cited as reasons for not providing initial review by experts at the present time. Many indicated, however, that the idea should be given serious consideration when budgets became sizable.

A staff member of one State Council indicated that the review of applications was conducted exclusively by the State Council. This took the form of an initial review by a subcommittee of Council which then presented recommendations to the full Council. If a subcommittee member felt that the discussion of a given project represented a conflict of interest, he could remove himself from the room during the deliveration. No decisions were reached without consensus of all members of the subcommittee. Each application was read by a primary and a secondary subcommittee member who were chosen at random. Final budget negotiations were delegated to staff with instructions that if after such negotiations uncommitted money remained, they should search out new projects for funding which reflected agreed upon priorities: geographic distribution of DDA funds and services; state priority listings as determined in their state plan; needs of clients and the regions for additional projects and the possibility that a project submitted and not funded had the potential to be reworked to a point where it could be approved and had the capability of delivering the service if approved.

This same State Council arrived at two important decisions: (1) the advocacy role should properly be funded through the volunteer agencies, and (2) a "grants writing seminar" should be conducted prior to the next grants application time. The major aim of the grants writing seminar is to help the less sophisticated potential recipients of funds to learn how to write a good application.

A Council member from another state agreed with the advisability of having the initial review done by experts who are not members of the State Council but indicated that at the present time such a mechanism is not in operation. Initial summaries are now prepared by staff and forwarded to all committee members. At the same time, applications and summaries are sent to four groups who have the right to comment on them but do not have the right of veto. These are: (a) the appropriate state agency (special technical assistance may be requested and/or provided by these state service agencies), (b) regional planning group review (the region selects priorities and makes recommendations), (c) technical assistance (by staff or based on agency response), (d) outside professional reader help (to get objective reaction to proposals; this is optional and is used for appropriate selected proposals). In addition to review by the four groups listed above, staff of this Council meet personally with applicants who wish to discuss their proposal. Finally, a summary is prepared by staff. Proposals and final summaries are then presented to a subcommittee of the Council known as the Proposal, Procedure and Review Committee. Members who may have a vested interest in a specific proposal(s) are excused from committee deliberation and discussion of that proposal(s). Optional use of outside readers on selected proposals is possible. The committee uses a rating schedule and discusses each proposal. Finally, it prepares recommendations for the State Council.

Ensuing discussion brought out the fact that a number of State Councils operate in substantially the manner outlined above. Many Council members expressed concern over the problem of how to prevent the "rich getting richer, and the poor getting poorer," as a result of the distribution of Developmental Disabilities funds. Suggestions included (a) having staff meetings in rural areas, (b) sending program information to a very large list of possible applicants, and (c) holding grants writing seminars.

A staff member from a third State Council indicated that the review of applications was substantially the same as that of the first State Council mentioned in preceding paragraphs.

An overall summary of the important points brought out in all of the discussions included the following points made by the Chairman:

1. All programs and plans for distributing funds are very new and all State Councils were faced with an almost impossible task of devising ways and means with very short deadlines.

2. It is very important to provide initial review of all applications by experts who are not members of the State Council.

3. This initial review group should report to the Council and the Coun-

cil must make the final decisions.

4. Staff should discuss each disapproved application with the applicant in an effort to find other possible sources of funds.

5. It is important for State Councils to develop policies separating service grants from planning grants.

6. State Councils should establish policies which will make it possible to serve all areas included under Developmental Disabilities. The chairman granted that establishing a proper balance is extremely difficult but cautioned State Councils not to allow their individual self-interests to make them provincial.

7. The chairman concluded the discussion by stating his conviction that he has seen lots of evidence that state groups are developing real sophistication. He is optimistic about the future of the Developmental Disabilities Program.

Part X
Innovative Programs and Sources of Funds

Editor's Notes

In addition to serving as a general forum for learning about the philosophy and operation of the Developmental Disabilities program, the planner of the National Conference viewed it as a marvelous opportunity for members and staff of state councils to share experiences and viewpoints. This objective clearly was achieved through the many informal contacts which took place among the nearly 800 conference participants.

Besides these informal interchanges, William Allen Ziegler, Jr. presented a paper summarizing some of the more interesting and innovative ways states were using DDSA funds to accomplish their objectives. Among the specific projects he reviewed were (1) the development of a statewide system of protective services for DD clients in Ohio; (2) the establishment of a statewide information and referral system in Louisiana; (3) the creation of a DD coalition in New Jersey; (4) the launching of community alternatives to institutional care in Washington State, Georgia and Montana, and (5) reaching out to the American Indian population in Colorado.

Given the limited funds thus far available through the DDSA program, the age old question of where to find adequate resources to meet the needs of the developmentally disabled was a constant source of conversation at the November conference. Tadashi Mayeda's paper on "Little Used Funding Options" is addressed to this question. He discusses a number of possible avenues for supporting DDSA activities through the U.S. Departments of Housing and Urban Development, HEW, Agriculture, Defense, Interior, Labor, Justice, Commerce and Transportation as well as the Veterans Administration, the Civil Service Commission, the General Services Administration, the United States Postal Service, the Appalachian Regional Commission, the National Science Foundation and ACTION. Numerous examples are included of how these various programs have been used by innovative and imaginative administrators to aid the developmentally disabled. The author also suggests 12 guidelines to follow in seeking funds from departments or agencies not usually associated with developmental disabilities programs.

New and Successful Programs and Projects

William Allen Ziegler, Jr.

INTRODUCTION

In the last ten years significant progress has been made in improving and expanding services for the mentally retarded. Many states have begun to develop an array of community-based services to diminish the need for long-term institutional care. In addition, alternatives to residential living (group homes, hotels, apartments, half-way houses, etc.) have been designed to incorporate the retarded child and adult into the everyday activities of community life.

One lesson of the past decade is that in order for the concepts of community services and alternate living modules to become a viable reality, effective liaisons between federal, state and local governments and also the private sector have to be cultivated. The recommendations of the President's Panel on Mental Retardation provided the framework for such progress in the early 1960's. One of direct outcomes of the Panel's efforts was the enactment of the Community Mental Retardation Facilities Act of 1963 (P.L. 88-164). This legislation was an important initial step in developing a federal, state, local partnership in improved services to the retarded. However, it was not until the signing of the Developmental Disabilities Services and Construction Act of 1970 (P.L. 91-517) that the groundwork for a full partnership relationship was completed. P.L. 91-517 broadened previous legislation (P.L. 88-164) by: (1) expanding the definition of the target group to be served; (2) authorizing support for a continuum of services in addition to construction of facilities; and (3) providing states with greater responsibility for planning and implementing the program through a formula grant program.

Despite the frustration surrounding the inadequate level of initial funding and the difficulties encountered in operationalizing the unique concept underlying the Developmental Disabilities Program, a number of excellent examples are already available of effective utilization of DDSP funds. The purpose of this paper is to provide a few illustrations of innovative uses of Developmental Disabilities funds.

FILLING GAPS IN SERVICES

One of the basic premises underlying the legislation is that DDSA funds should be used to plug up existing gaps in a state system of delivering services to the developmentally disabled rather than simply supplant ongoing efforts. Several jurisdictions have demonstrated the viability of this approach by using federal dollars to demonstrate new and successful models of the delivery of services to developmentally disabled clients.

Ohio is a good illustration of this approach. Soon after its establishment, the state DDSA planning and advisory council designated protective service for substantially disabled adults as its highest priority area of interest. About this same time Governor Gilligan signed into law a bill which authorized the development of a statewide system of protective services. The Division of Mental Retardation, working with the State Developmental Disabilities Council, designed a case management module which encompassed case management, protective services and personal advocacy – plus auxiliary services of information and referral and follow-along.

DDSA funds are now being used as leverage money to get this innovative new system off the ground. The state agency is administering the case management and protective services programs while a coalition of voluntary groups is carrying out the advocacy portion of the plan.

The delivery of services will emanate from the state's zonal centers. Each of these 12 regional centers will have a trained protective service specialist who will be directly responsible to the protective service administrator in the central office. Therefore, the monitoring system will be divorced from the delivery functions of the Division of Mental Retardation. These workers will assist the developmentally disabled individuals to manage themselves and their affairs. To accomplish this gargantuan task, an array of services will be provided: outreach, counseling, case auditing, guardianship, legal intervention, follow-along, and case management. A computerized tracking system will be utilized to provide effective information and referral and follow-along services.

For several years, the consumer-oriented organizations have played an important role in developing Ohio's protective services and citizen advocacy programs. In 1967, the Ohio Citizens' Committee for Mental Retardation Planning launched a protective services project in three locations which has since been administered by the Division of Mental Retardation. The monumental protective services and public guardianship bill was spearheaded by the Ohio UCPA and ARC with support from the Division.

Representatives from the Ohio Association for Retarded Children, the Epilepsy Foundation and the United Cerebral Palsy Association will be entirely responsible for the advocacy function of this module. Guidelines have been developed and a pilot project has met with initial success. This year the consumer interest groups will be supporting a limited number of personal advocacy projects and employing a director to assist in the statewide development of the advocacy system.

The spirit of cooperation between the state agency and consumer interest groups throughout the design and development of the case management system typifies the partnership approach which must underlie successful efforts on behalf of the developmentally disabled.

ACCESSING THE SERVICE SYSTEM

There has been a growing national awareness of the need for improved access to information on generic and special services available to mentally retarded children and adults. The importance of timely, accurate information on service resources is not restricted to parents and interested community groups but also includes state agency officials. *Louisiana* is now in the process of developing such a statewide information and referral system through the use of developmental disabilities funds.

The central element in this new system will be the designated staff members in a variety of generic health, social and educational agencies throughout the state. These staff members will be trained to serve as their agency's specialist in information and referral services for the developmentally disabled and their families.

Besides the instruction and development of the staff, the DDSA funds will be used for: (1) the preparation and publishing of a statewide directory of services available to the developmentally disabled; (2) the development of a standardized referral and followup process; (3) the design and implementation of a computerized registry of cases; and (4) the utilization of collected data to evaluate management, to provide feedback to individual workers and to assure that clients receive better access to services.

The Louisiana Division of Mental Retardation, the state agency which is responsible for administering DDSA funds, has contracted with a private management consulting firm to design and implement this computerized information and referral system. In instituting this program, the firm will be responsible for the initial training and development activities.

The consulting group will also prepare the directory of services available to the developmentally disabled. This directory will include, as a minimum, the following data: (1) the identity and location of services; (2) the description of the available services; (3) the referral processes that must be followed; and (4) the financial policy for each service provided.

The concept of an effective information and referral system in Louisiana is not novel to the state. Several years ago a state directory of services for the mentally retarded was prepared as a result of the initial federal comprehensive mental retardation planning legislation (P.L. 88-156). In addition, two local information and referral centers were instituted under the aegis of this act. The results of these activities have demonstrated the feasibility of creating a statewide information and referral network.

A project in Georgia provides another excellent example of how DDSA funds can be used for impact on other potential generic service systems. Through a DDSA grant a therapeutic recreation consultant has been added to the staff of the Georgia Department of Natural Resources. The program has been designed to: (1) evaluate the recreational needs of the developmentally disabled; (2) develop local recreation programs for this segment of society; (3) recruit and train recreational specialists for the developmentally disabled; (4) establish recreational standards for this group; and (5) work towards eliminating architectural barriers in public facilities.

FORMING NEW DEVELOPMENTAL DISABILITIES COALITIONS

As outlined in the report of President Kennedy's Panel on Mental Retardation, coordination and planning are essential elements of the organization of services in any system. Coordination can only be accomplished through communication, cooperation and clear lines of authority.

The *New Jersey* Committee for the Developmentally Disabled, a coalition of voluntary agencies representing and/or serving the developmentally disabled, has capitalized on this concept and is operating as an effective adjunct to the state DDSA Planning and Advisory Council. The Committee is composed of representatives from the New Jersey Association for Retarded Children, the United Cerebral Palsy Association of New Jersey, the New Jersey Chapter of the March of Dimes, the New Jersey Epilepsy Foundation, the New Jersey Association for Children with Learning Disabilities, and the New Jersey Easter Seal Society for Crippled Children and Adults.

Primarily, the group coordinates planning and program activities of the member voluntary agencies to best serve the interests of the state's developmentally disabled. The Committee's project coordinator, who was employed through a DDSA staffing grant, works closely with local organizations to help design the most comprehensive program, to find new funding sources, and to avoid duplication of services.

A second DDSA grant has been awarded to the Committee for the development of a statewide, computerized information and referral system which has stimulated the interest of other voluntary groups to join in the endeavor.

Although the Committee is only represented by groups from the private sector, staff members of the state DDSA Council do participate in the Committee's meetings and vice versa. This liaison has fostered an effective communication linkage. The state agency has become aware of the consumers' needs and priorities and, in turn, has been able to transmit its goals and objectives to the representatives of the developmentally disabled.

The creation of the Committee stemmed from early planning for the implementation of P.L. 91-517 in New Jersey. The Mental Retardation Planning Board, the predecessor to the New Jersey DDSA Planning and Advisory Council, felt the need for informing the public of the "DD concept." Therefore, representatives of the Board and consumer agencies held a series of formal and informal meetings. At the conclusion of these sessions, the voluntary agencies determined that they had a need to continue this interaction in a formal manner.

STIMULATING COMMUNITY BASED SERVICES

As indicated above, one of the basic concepts underlying the Developmental Disabilities Act was that service should be delivered to retarded clients just as near as possible to their home communities. California is an example of a state which has been pursuing the goal of community-based services since the early 1960's.

Two regional centers were established as an outgrowth of comprehensive statewide planning in 1963-64. In 1968, the *California* legislature directed a study of the program and services available to the state's retarded population. The Lanterman Mental Retardation Services Act of 1969 grew out of this study.

This Act provided for filling gaps in services, joining fragmented services and tailoring services to the needs of mentally retarded individuals. The Lanterman Act, among other things, called for the completion of a statewide network of 13 regional centers. Each center serves as a fixed point of referral in the community to coordinate the continuum of services to the retarded person.

A major portion of California's DDSA allotment is being used to supplement state funds in order to complete the development of regional centers. The four newest centers will serve not only the retarded but also all developmentally disabled individuals. All of the centers are operated by private, non-profit, local organizations with a full professional staff. The services are provided without charge and include: diagnosis, counseling, case registry, guardianship, case management, and follow-along.

California's regional centers are beginning to provide retarded persons and their families with an alternative to institutional living.

CREATING NEW MODELS OF SERVICE

The developmental disabilities program emphasizes the need to develop and test out new models for delivering services to clients. One such model, which has gained popularity over the past few years, is the group home or hostel. Rather than carting off retarded persons in need of residential service to some distant custodial institution, the group home concept stresses the importance of maintaining the individual in a small, community-based residence where he will have an opportunity to participate in school, vocational training, employment, sheltered work or developmental activities.

The State of *Washington* has been a forerunner in the development of group homes. For example, three small apartment-type houses have been in operation for the last three years at Fircrest School just outside Seattle. This alternative living situation was designed to train retarded clients in the basic skills of community living.

The Office of Developmental Disabilities, the state agency responsible for community and residential programs for the developmentally disabled as well as deaf-blind programs, now has broadened the halfway house concept. One apartment complex has been converted to serve retarded deaf and hard-of-hearing persons (18 years or older) who are in need of guidance in urban living skills.

The project is being supported through a federal grant under Section 4a(1) of the Vocational Rehabilitation Act, under funding authority administered by HEW's Division of Developmental Disabilities.

The program will serve two populations of deaf or hard-of-hearing individuals: the mildly and moderately retarded and those persons from culturally or service deprived environments. Primary consideration will be given to institutionalized, deaf retarded persons.

The participants will actively engage in the training program for a 12-month period with major emphasis being placed on the conversion of basic self-care, vocational and practical academic skills into methods for surviving in an urban community setting. Role playing, group discussions, private counseling and special classes will help prepare the clients for independent living. A local community college also will offer adult education classes in "Survival Behavior" to the group.

Only in isolated instances will the facilities and services at Fircrest School be utilized. Every effort will be made to have these handicapped persons perform in the community—recreation, shopping, banking, and health services.

Community services have received formal endorsement in *Georgia* with the recent enactment of mandatory community services legislation S.B. 347). The purpose of the law is to authorize the development of community alternatives to total institutional care.

To begin implementing this legislation, the Division of Mental Health in the Georgia Department of Human Resources has designed a plan for a network of group homes throughout the state. Initially only thirteen residences will be rented or leased; however, the division ultimately plans to expand the program to 300 group homes.

The first phase has been partially funded through a DDSA grant. One group home will be opened in each of the state's 13 health district and will be operated under the supervision of the district mental health chief. Each project will be established in a locality with suitable recreational, work, educational, and training activities.

The target population for the initial homes will be mildly and moderately retarded children and adults who are presently institutionalized. Every activity in the program will be directed towards simulating a typical family environment. Each client will participate only in his or her work, education or training program outside of the home and return in the afternoon for recreation, household chores, or other group activities.

Montana has utilized three different HEW funding mechanisms to implement a preschool program for children who exhibit learning disabilities and/or physical handicaps. The HEW Division of Developmental Disabilities administers two of the funding programs used in the program—DDSA formula grants and the Hospital Improvement Program (HIP).

The program is designed for children, 3 to 7 years of age: (1) to determine each child's full potential; (2) to help the child develop to his fullest potential; and (3) to prepare the child for appropriate school programs in his community when he reaches school age. The preschool curriculum consists of motor skills development, speech and language development, and socialization and self-help activities.

Since some of the children must travel great distances to attend the preschool, arrangements have been made to provide community-based housing for them. This housing project is funded through a HIP grant. Living accommodations are provided on a five days a week basis. On weekends parents must arrange to have their children at home.

The developmental disabilities grant covers the ancillary services to the preschool program. These supplementary services include consultations, transportation, and physical and speech therapists.

Services are provided on a regional basis in order to reduce the need for institutionalization. Many of the children reside at home and are transported daily to the program by their parents.

The third funding source is Title III of the Elementary and Secondary Education Act. Through this grant the academic preschool program is funded–that is, staff, supplies, equipment, etc. The project staff consists of two teachers and one teacher aide.

The Regional Interagency Council, a community voluntary organization, coordinates and oversees the entire project. The Montana Division of Mental Retardation sees this triple-funded preschool program as a prototype of a much more comprehensive community-based service delivery system.

SERVING SPECIAL TARGET POPULATIONS

Due to the clear linkage between poverty and cultural-familial retardation among poor, deprived subgroups in our society, the Developmental Disabilities Act places special emphasis on reaching out to the poverty stricken. This is one of the purposes for which funds for projects of national significance may be used; in addition, a higher matching ratio is provided for poverty area projects and states are required to spell out in the state plans what steps are being taken to serve the developmentally disabled from poor families.

A project for the Ute Mountain Indian Tribe, which is located in an economically depressed area of *Colorado* is a unique example of how one state is attempting to make services available to a group that was unserved in the past. The project's primary purpose is the implementation of an early intervention program for the Ute Mountain children under three years of age in order to deter cultural retardation. Parent training and involvement are basic to the child stimulation project.

As the project progresses, participation of the entire tribe is expected. The project director has been selected from the Ute Mountain Tribe. He and his staff are designing their program to fit the surrounding culture. In order for the educational system to be effective the new pattern must be adapted to the youths' everyday culture.

Initially, interaction with outside agencies was slow; however, a rapport has now been established between the two cultures. The external groups are assisting in developing new funding sources, legislation and other resources essential to the project. In cooperation with the tribal council and local community, the Colorado Division of Mental Retardation, the Bureau of Indian Affairs, and several other state and federal agencies and consumer groups are participating in the project.

The program is aptly titled, "A Return to Cultural Dignity." As the program develops, the tribe will be able to understand more fully the other cultures, to resolve community problems, to deter economic depression and to stimulate cultural respect and learning within their own children.

For the continuation of the project, the HEW Office of Child Development, VISTA volunteers from ACTION, the John F. Kennedy Development Center outreach program, and other tribal, community and state agencies are projected as future funding and manpower resources. It is hoped that the Ute Mountain project will be not just another early intervention program but also a demonstration of an acculturation process with national impact.

CONCLUSION

During the past decade all levels of government, along with the private sector, have joined in orchestrating effective and cooperative programs in the community for mentally retarded children and adults. Concerted effort has been concentrated on developing new federal, state and private funding sources. Although the DDSA formula grants have been limited, there are a number of examples of how these monies have been used to fill gaps in services, to launch innovative, new programs and to attract other dollars and manpower and materiel resources necessary for continued program expansion.

For a program for the developmentally disabled to be labeled a success, it must not only be initiated but also must continue. Therefore, in-depth preliminary and subsequent planning must be fully coordinated with all related governmental and private agencies and must take into account primary and alternate funding sources.

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Little Used Funding Options

Tadashi A. Mayeda

INTRODUCTION

Two workshops were held on "Little Used Options (for funding programs to serve developmentally disabled persons)" at the November 1972 National Conference of State Planning and Advisory Councils in Washington, D.C. The workshops were aimed at identifying infrequently used sources of funding which could provide flexibility in program development.

The notion that seemingly unrelated sources of funds are available to developmental disability organizations was supported by scattered examples of funding such as the construction assistance of the National Children's Center in Washington, D.C., by the Economic Development Administration of the United States Department of Commerce; assistance in the movement of institutional residents in Tennessee to community facilities through rent subsidies provided by the Department of Housing and Urban Development; the employment of discharged institutional residents in newly established institutional jobs through Emergency Employment Act funds of the Department of Labor; the support of clinical and sheltered workshop programs in Ohio and Georgia by the Appalachian Regional Commission; and food preparation subsidies to various day programs through the United States Department of Agriculture. In fact, with the exception of the Treasury Department, examples of developmental disability program support could be found in all Federal departments and many executive agencies of the Federal Government.

Although optional sources of Federal funding were the focus of the workshops, it became abundantly clear as the workshops progressed that these options should include unusual ways to serve the developmentally disabled through traditional channels of funding such as the use of Title IV-A for summer residential camping programs and the use of general state funds for programs such as the training and rehabilitation of retarded delinquent youth in the State of North Carolina.

In the workshops, the author started with a Federal outlook on unusual sources of funding. This included the child development programs of the Appalachian Regional Commission, the genetics research programs of the Veterans Administration, and other Federal programs such as the manpower outlook of the Department of Labor. To this, Dr. Erwin Friedman, the Director of the National Children's Center, added the unusual situation of construction support by the Economic Development Administration and, particularly, the circumstances surrounding the negotiations which led to financial assistance.

John Horn, representing Robert Denny, the Executive Director of the North Carolina Coordinating Council, and staff members of the Council described one of the few organizations in the United States funded through the State to implement the recommendations which were federally seeded in the early years of planning on behalf of the mentally retarded. The effect of planning in the early '60's rippled through many of the departments in the State of North Carolina so that ventures such as specialized correctional programs for mentally retarded youth and career opportunities for high school and undergraduate students, just now being discussed in many states, are established programs in that state.

Alvin Sheetz and colleagues of California, Pa., described one of the few, if not the only, program in the United States in which carpenters, plumbers, and other members of the building trades collaborate with a voluntary association and the Departments of Special and Vocational Education to mount an aggressive building/training program for youth in special education classes. In this case, an unusual coalition, rather than unusual source of funding, led to a program which serves low income homebuyers as well as youth with special needs.

Finally, Vernon Lindsay, the Executive Director of the North Dakota Association for Retarded Children, described numerous programs being supported by Federal departments other than the Department of Health, Education, and Welfare. These included partial reimbursement for costs of food provided to nonresidential clients of daytime programs, an imaginative use of the Department of Agriculture's commodity distribution program, food equipment and food handling reimbursement, and housing development through the Department of Housing and Urban Development.

The author and all of the resource people, without contradiction, both warned against the pitfalls and encouraged the search for and use of alternative sources of funding for developmental disabilities programs. The process is tedious; and, more often than not, applicants are turned away by local program offices. Nonetheless, the rewards suggest that the effort is worthwhile and that many program alternatives, which might otherwise not come into being, can be realized.

OBJECTIVES AND LIMITATIONS

The need for workshops on "Little Used Options" was, to a great extent, caused by the inability of the Department of Health, Education, and Welfare to finance programs authorized by Congress. In fiscal year 1971 the congressional authorization to DHEW exceeded that department's actual appropriation by $6 billion[1] –a fiscal gap reflected in the budget of the Developmental Disabilities Division of the Social and Rehabilitation Service, the prime supporter of programs for the developmentally disabled in the Federal government.

The inability of the Federal government to finance authorized programs, coupled with the trend to embrace larger numbers of "developmentally disabled" persons in program authorizations, have led many organizations to seek support from sources other than DHEW. Financial necessity and, in some cases, program alternatives not otherwise possible were the principal reasons for seeking other funding options.

Plain as the reasons might be for seeking other sources of support, it must be remembered that, despite the number of cases cited, the total expenditures of the Department of Labor, Department of Commerce, Justice Department, Department of Agriculture, Appalachian Regional Commission, Civil Service Commission, and all other Federal departments and agencies probably do not exceed the expenditures of the Department of Health, Education, and Welfare for the developmentally disabled.[2] It is likely that state and local contributions on behalf of the developmentally disabled are proportionately insignificant.

Nonetheless, readers are encouraged to seek little used sources of support. This is said with the hope that succeeding awards from the same department or agency might become easier to obtain as local representatives are persuaded to include the developmentally disabled in their future program plans.

Apologies are offered by the author for his Washington, D.C., viewpoint of little used funding options. The author has only a vicarious appreciation for the many pitfalls and hurdles of approaching regional representatives of Federal programs. The comments and suggestions of the resource people, all of whom have had the experience of qualifying for program funds, were particularly helpful from the "field" viewpoint.

WORKSHOP SUGGESTIONS

Suggestions on how to go about obtaining funds from departments of agencies not usually associated with developmental disabilities programs were made to workshop participants by the author and the resource people. The participants undoubtedly sensed that some were germane only to a given locale or situation, that others were timely only during the early years of a program, and that only a few were generally applicable to all service organizations regardless of location. With these limitations in mind, some of the more commonly suggested actions were as follows:

*1. **Imagination.*** Dr. Friedman convinced the Economic Development Administration to fund the National Children's Center on the basis that it was an "economic enterprise" in an economically depleted area.

*2. **Persistence.*** Vernon Lindsay's housing developments started in North Dakota and were pursued from there through local housing authorities, regional offices, and the Department of Housing and Urban Development before the matter of subsidies was resolved in favor of the dependent adults in question.

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[1] Richardson, Elliott: "Responsibility and Responsiveness; the HEW Potential for the Seventies," DHEW Publication No. (OS) 72-19. January 1972.

[2] The President's Committee on Mental Retardation: "Federal Programs for the Retarded." June 1972.

3. Related Sources. Solicitations should start with sources of support most related to the problems of the developmentally disabled. Minimally, these should include the food services offered through the Department of Agriculture and the child care and development programs of the Appalachian Regional Commission.

4. Phraseology. Soliciting organizations must obtain applicable program guidelines and be familiar with these prior to soliciting assistance. The language of solicitation must be phrased in terms familiar to the awarding agency. For example, children in foster homes while loosely referred to as "families" by social service agencies are not legally families from the viewpoint of HUD.

5. Eligibility. Soliciting organizations must determine which groups are eligible for support under different programs. Under the HUD Model Cities program, for example, eligible recipients are "any municipality, county, or other public body having general governmental powers."

6. Find a Liaison. Having determined what groups are eligible, soliciting organizations must find a "brother" (in the words of Lindsay) in that organization. Together they can find ways to meet the needs of the developmentally disabled.

7. Communication. Soliciting organizations must establish channels of communication with regional or local program administration offices. These should include local housing authorities, regional offices of Federal departments many of which are not co-located,[3] and various State departments which receive formula funds through congressional legislation.

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[3] Office of Management and Budget: "Catalog of Federal Domestic Assistance," 1972.

8. Seek All Possible Sources. Each organization should assign a person(s) to seek and follow up on all prospective funding clues. That person should obtain and review monographs such as the "Catalog of Federal Domestic Assistance" (published annually by the Office of Management and Budget, now out-of-print but usually available in DHEW regional offices) and "Federal Programs for the Retarded," published by the President's Committee on Mental Retardation. They should subscribe to "New Directions," published by the National Association of Coordinators of State Programs for the Mentally Retarded in Arlington, Va., "Programs for the Handicapped," published by the Office of MR Coordination in DHEW, and the publications of the National Association for Retarded Children, the United Cerebral Palsy Associations and the Epilepsy Foundation of America. Clues to new sources of funds can also be found in the publications of the Day Care and Child Development Association of America and various rehabilitation associations.

9. Request Guidelines. Program information and guidelines should be requested from regional offices based on clues found in these publications.

10. Match Need to Guidelines. Examples of unusual funding should not be copied literally but adapted to the problem on hand. Local needs should be matched to guidelines and interpretation of guidelines by local offices. Soliciting organizations should be mindful of the fact that there are local variations and changes in contract or grant awards.

11. Submit a Project Synopsis. Soliciting organizations should take advantage of the common practice of allowing (or sometimes encouraging) solicitors to submit a synopsis of a proposed project before investing in a detailed proposal.

12. Watch Trends. Soliciting organizations must be mindful of new trends developing in Washington, D.C. and must guage their actions on these trends. For example, signs that Federal programs were decentralizing appeared four years ago. Relations with state and regional personnel should have started early based on those signs.

FEDERAL PROGRAMS

In recent years, there has been a growing awareness that developmentally disabled person qualify for the benefits of programs not necessarily aimed in their specific direction. The developmentally disabled are often members of the same priority groups and live in target areas that are the focus of many Federal programs.

The developmentally disabled can qualify as members of low income groups, residents of economically depressed areas, as unemployed or underemployed individuals, or otherwise dependent persons. As anyone of these target populations they are sometimes eligible for housing, food, or employment assistance from the Federal government.

The potential of programs, which are unrelated to the specific health, development, and social needs of the developmentally disabled, is considered to be good if for no other reason than they have been under-utilized by service organizations. Many serious barriers, however, do exist and these will have to be removed before a full range of services can be provided to the developmentally disabled. As national service organizations, congressional leaders, and advocates in the Executive Branch of the government identify these barriers and find ways to resolve inequities, the situation will undoubtedly improve. It is the purpose of this section of the paper to provide clues on what now can be provided to the developmentally disabled. Readers are cautioned that the developmentally disabled are not automatically eligible for these programs and that the conditions for award, as prescribed by each of the program offices or as interpreted by each of the field offices, should be examined carefully.

Housing

Options:

Department of Housing and Urban Development (HUD)
Department of Agriculture (USDA)

Where both HUD and USDA are concerned with housing for the low income family, HUD focuses on the urban problem while USDA emphasizes the needs of the rural family.

HUD programs often require local support, i.e., recommendation of approval by a local governmental unit or community action group. This is a requirement of Model Cities and the Neighborhood Facilities programs. Rent Supplement payments are made on behalf of tenants to owners of rental projects which are a part of an approved, workable program for community improvement.

Some relief in providing community housing for the dependent developmentally disabled might be expected due to the recent modification of HUD eligibility requirements. Certain provisions of the National Housing Act had previously been limited to the physically handicapped only. This interpretation was broadened to include the organically damaged, handicapped individual. A legislative modification to the National Housing Act is seen as the only clear route to qualifying all developmentally disabled persons for these housing benefits.

The issue of housing support for developmentally disabled minors in foster homes is not clear. Under certain circumstances, groups of minors under the care of foster parents do not qualify as a "family" and are sometimes ineligible for housing assistance.

The USDA, through the Farmers Home Administration and its field offices in 39 states, administrates rural housing loans, rural rental housing loans, housing repair loans, and self-help housing technical assistance. In general, these programs are designed to assist rural families to obtain decent, safe, and sanitary dwelling and facilities. Direct loans, guaranteed/insured loans, and direct technical assistance are included as types of assistance available through these programs. Of the 20 rural credit programs administered by the Farmers Home Administration, 5 are reported to be directly applicable to the developmentally disabled.

Food and Living Assistance

Options:

Department of Health, Education, and Welfare (DHEW)
Department of Agriculture (USDA)
Department of Defense (DoD)
Department of Interior
Veterans Administration (VA)

Assistance available through DHEW and USDA is broader than that available through DoD, Interior, and the VA. The latter three agencies are concerned primarily with military personnel, military dependents, or Indian tribes.

Food assistance and food preparation subsidies are available through the five regional offices of the USDA Food and Nutrition Service. Many of the daytime programs of non-profit organizations serving the developmentally disabled are eligible for assistance through affiliations with public schools or as independent non-profit organizations.

Distinction should be made between commodity distribution and food assistance programs. The former, aimed at the cultivation of farm markets, must be used selectively.

Lindsay reported that the costs of obtaining reimbursement under food assistance programs (partial repayment for actual meals served) can be high if handled by each day program. Central accounting services are used in North Dakota to handle reimbursement requests for all eligible Association programs in the State.

Work and Economic Security

Options:

Department of Health, Education, and Welfare (DHEW)
Department of Labor
Appalachian Regional Commission (ARC)
Civil Service Commission (CSC)
General Services Administration (GSA)
United States Postal Service (USPS)

Work and economic security programs in DHEW are located in the Social and Rehabilitation Service or the Social Security Administration. These are commonly known options and will not be discussed further.

The Department of Labor's activity on behalf of the developmentally disabled is carried on chiefly through the Manpower Administration and the Employment Standards Administration. Under the authority of the Manpower Training and Development Act, the Economic Opportunity Act, and various Social Security Amendments, the Manpower Administration administers programs such as On-the-Job Training, Neighborhood Youth Corps, Operation Mainstream, Work Incentives, Public Service Careers, Public Employment, and Emergency Employment. All of these programs have, in some way, provided training or job opportunities for the developmentally disabled. The Employment Standards Administration is responsible for wage and hour-and-wage compliance programs which are used to prevent curtailment of job opportunities for the developmentally disabled.

The ARC administers vocational education facilities and operations and vocational and technical education grants programs which, depending upon local initiative, can be used to help persons to obtain employment at their best capability. Various workshop assistance programs for the handicapped have been reported by the ARC.

GSA programs for the developmentally disabled fall primarily in the areas of contract opportunities for sheltered workshops and the provision of loan or surplus equipment to organizations serving the developmentally disabled. Contract opportunities available through the Wagner-O'Day Act since the Act was amended in 1971 to expand preferential treatment in bidding on government contracts to sheltered workshops despite the initial, high priority for the blind. (The program benefits were previously limited to the blind.)

The CSC and USPS are involved mostly in providing jobs for the developmentally disabled. A Federal program of employment (for the handicapped) is administered through the CSC. The Commission, through various agencies of the Federal government in all states, employs 3,800 mentally retarded individuals. How many other developmentally disabled individuals are employed through CSC is not known. Over a third of the above are employed in the District of Columbia, Maryland, and Virginia. The balance are scattered in civil service jobs throughout the United States.

Family Development and Assistance

Options:
- *Department of Health, Education, and Welfare (DHEW)*
- *Department of Agriculture (USDA)*
- *Department of Interior*
- *Appalachian Regional Commission (ARC)*
- *Veterans Administration (VA)*

General assistance in family development is available to Indians through the Department of Interior, to residents of the Appalachian States through the Appalachian Regional Commission, and to other select groups through organizations such as the Veterans Administration. Programs of the USDA appear to offer the greatest potential in this area.

Educational programs based on local needs in the areas of home economics and youth development are administered through designated land-grant institutions by the USDA Extension Service. Through these programs, many examples have been found of disabled youth being prepared for community living through extension programs of housekeeping, budgeting, all aspects of personal and family management, and work preparation. Extension programs of interest to organizations serving the developmentally disabled include the Expanded Food and Nutrition Program, Family Life Program, Family Resources Management Program, 4-H, and Community Resource Development.

Nurture and Protection

Options:
- *Department of Health, Education, and Welfare (DHEW)*
- *Department of the Interior*
- *Justice Department*
- *Veterans Administration (VA)*

The programs of Interior and the VA are aimed at special interest groups.

The Institutions and Facilities Office of Justice's Civil Rights Division, established in September, 1971, is charged with and has recently been active in protecting the rights of persons committed to institutions. Although not directly involved in providing services to the developmentally disabled, their impact in the area of civil rights will be significant.

The Law Enforcement Assistance Administration is the second organizational unit in the Justice Department concerned with the problems and needs of the developmentally disabled. Authorized under the Omnibus Crime Control and Safe Streets Act of 1968, requests for discretionary grant support have been submitted by organizations serving the developmentally disabled only after the LEAA was well underway and probably too late to be considered in the initial selections. With the exception of North Carolina, State plans have not indicated that block grant funds will be used to serve the developmentally disabled.

Research and Prevention

Options:

Department of Health, Education, and Welfare (DHEW)
Department of Agriculture (USDA)
Department of Housing and Urban Development (HUD)
Appalachian Regional Commission (ARC)
National Science Foundation (NSF)
Veterans Administration (VA)

The involvement of USDA in nutrition has been long and deep. National Science Foundation programs are more recent. The Veterans Administration claims to have a broad spectrum of interest in research topics related to the field of developmental disabilities. HUD interests are confined primarily to effects of lead poisoning on children. Child development and the many forces that tend to affect the child are subjects of interest to many departments and agencies.

Other Areas of Interest

Options:

Department of Commerce
Department of Transportation (DoT)
ACTION

Commerce's Economic Development Administration is charged with the responsibility of assisting communities which suffer from substantial and persistent unemployment. Authorized under the Public Works and Economic Development Act of 1965, as subsequently amended, the program is administered through six regional offices. Only one case is known in which an organization serving the developmentally disabled has been able to qualify for construction funds. (See the following section).

In the Department of Transportation there are no categorical programs for the developmentally disabled, however, the Department feels that many of the public carrier design and regulation programs have some bearing on the needs of this group. Recommendations have been made to DoT to ensure the safety of the developmentally disabled in public carriers, to use safety training towns to teach the developmentally disabled how to become more mobile in communities, and to subsidize these individuals for transportation not otherwise available.

ACTION is involved in volunteer programs which benefit the developmentally disabled. Among these are the Foster Grandparents program, Volunteers in Service to America (VISTA), Service Corps of Retired Executives (SCORE), and Active Corps of Executives (ACE). Many cases are known in which volunteers directly help with developmentally disabled persons or the organizations serving them.

A SAMPLING OF LITTLE USED OPTIONS

Community Residential Living in North Dakota

Five residential units with 6 - 8 children in each unit are being developed under HUD 221(d)(3) mortgage insurance and HUD rent supplement funds in

North Dakota. Loans are guaranteed by the government and up to 70% rent subsidies to tenants will be allowed. For loan authorization purposes, each bedroom (not the entire building) is considered to be a unit.

> (N.B. 221(d)(3) is a National Housing Act program administered by Housing Production and Mortgage Credit of FHA to insure lenders against loss on mortgages. In this case it was tied together with the rent supplement program administered by the same agency. The program is administered through regional or local insuring offices of HUD.)

Clover Bottom Hospital and School Normalization Program

In early 1972, thirty Clover Bottom residents were moved to newly constructed apartments in the Nashville, Tennessee community. With the Financial assistance of the Federal Housing Administration rent subsidy program, the former residents, paying less than $25 per month, are able to manage on modest Old Age or Disability benefits. The transition was smoothed by donations and assistance from the Clover Bottom staff and community volunteers.

Model Cities

In various areas designated as model cities, the governing residents have chosen programs for the developmentally disabled as high priority items. Classes for mentally retarded children are sponsored by the Albuquerque, N.M., Model City; home health aides for the mentally retarded are being trained in New Orleans; and a special education kindergarten is sponsored in Texarkana, Texas. Depending upon local interest, projects range from special recreation, home services, and vocational training, to independent living assistance programs for developmentally disabled adults.

> (N.B. Model Cities Supplement Grants administered by Community Development of HUD will be replaced by the Urban Community Development Revenue Sharing program if enacted by Congress. Municipalities, counties or other public bodies having general governmental powers are eligible. Neighborhood residents play a role in governing and administering local programs and determining, to a great degree, local priorities.)

Neighborhood Facilities

HUD reports that the Neighborhood Facilities program, administered by Community Development, is a potential resource for organizations serving the developmentally disabled. Although no examples have been cited, service agencies are eligible for assistance in the construction or rehabilitation of community service centers through local public bodies, provided these facilities are shared with other community based organizations and are accessible to a significant proportion of the area's low or moderate income residents.

Iowa Foster Homes

Two communities, each involving 15 to 20 foster placements for mentally retarded adults, will be selected in Iowa as part of a program utilizing cash assistance payments to adults under Aid to the Disabled, county funds, and special demonstration funds from Section 1115 of the Social Security Act.

Emergency Employment in Pennsylvania Institutions

Department of Labor Emergency Employment Act funds have been used in Pennsylvania institutions to establish 300 positions for unemployed residents on discharge status. Placement priority is given to fully employable, discharged residents who have worked in the facility.

> (N.B. In early fiscal year 1972, $1 billion was appropriated to provide unemployed and underemployed persons with transitional jobs in needed public services. Administered by the Manpower Administration of the Department of Labor through a state designated official, all states and 650 cities and counties with more than 75,000 population have been designated responsible program agents. Apportionment of funds range from $1.5 million to $100 million per state. 90:10 federal matching is authorized with local share in cash or in kind.)

North Dakota Job Training

The NDARC has been involved in the Department of Labor On-the-Job Training program–most recently through the NARC–for six years. Clients, starting with no income now have a combined income of $304,000 in jobs started through the OJT program. After six years 58% of all clients are still in the same jobs for which they were trained.

> (N.B. Funded at the level of $20 million per year, the National On-the-Job Training program is administered through Manpower Administration of the Department of Labor Under the Manpower Training and Development Act, as amended. National organizations representing unemployed or underemployed persons who cannot reasonably be expected to obtain full time employment are eligible for cross regional or national programs. The National Association for Retarded Children (NARC), longtime recipients of OJT funds, have been contacting local units with invitations to participate.)

Neighborhood Youth Corps

Mentally retarded youth have been included in Neighborhood Youth Corps programs in the state and public schools. Administered by the Manpower Administration of the Department of Labor, the program is authorized under the Economic Opportunity Act and is designed to provide job opportunities to students of low income families. As in the case of the mentally retarded youth working on projects while attending classes, the program is designed to provide work experience while allowing youth to remain in school.

Public Service Careers

The Green Valley Hospital and School, Greenville, Tennessee, is a work site for training disadvantaged enrollees under the Department of Labor Manpower Administration Public Service Careers program. Authorized under the Economic

Opportunity Act of 1964, as amended, the program, allows occupational training and related services primarily to low income and disadvantaged persons. The program is managed through the eleven offices of the Regional Manpower Administration.

Employment of Older Adults

Older residents at the Bowen Children's Center in Harrisburg, Illinois, have been employed on grounds improvement under Operation Mainstream of the Department of Labor. The $83 million program, administered through Regional Manpower offices of the Department of Labor, seeks to provide work training and employment activities for chronically unemployed, poor adults. Funds are used primarily for the betterment and beautification of communities or areas served by the project.

Area Manpower Planning for Retarded Youth

All state governors and mayors of cities over 100,000 population are eligible for manpower planning funds from the Cooperative Manpower Planning System (CAMPS) of the Department of Labor. In New Orleans, because of the particular interest of a member of CAMPS, a six month survey of the needs of the mentally retarded was conducted. As a result of that survey attempts are being made to mobilize support for a center for vocational training of mentally retarded youth, a sheltered workshop, and an extension of community evaluation and work adjustment facilities.

Child Development in the Appalachian States

Seventeen hundred learning disabled children are served by Appalachian Regional Commission (ARC) funds in the New York southern tier. Funds have also been provided to the Schuyler (New York) County Early Childhood Education Program for Handicapped Children, the Exceptional Children's Day Care Center in Kingston, Tennessee, and the Jefferson County (Ohio) Child Development and Family Advocacy Center for home visits to families with mentally retarded children.

> (N.B. Child development funds are authorized to the 13 Appalachian states through Section 202 of the Appalachian Regional Development Act of 1965, as amended. The $18 million appropriated by Congress in Fiscal Year 1972 can be used in combination with Title VI-A funds for 100% Federal funding. ARC representatives are located in each of the 13 Appalachian states (Alabama, Georgia, Kentucky, Maryland, Mississippi, New York, North Carolina, Ohio, Pennsylvania, South Carolina, Tennessee, Virginia, and West Virginia).)

Health Programs in the Appalachian States

To the extent that developmental disabilities are identified as priorities by local councils funded under the Appalachian Regional Development Act, projects have been developed and funded for demonstration health programs in the Appalachian states. Projects exist in 12 of these states and include funds to a

3-county mental retardation project in Alabama, a sheltered workshop program in Georgia, an evaluation clinic in Ohio, and various regional mental health/mental retardation programs.

Camping for Mentally Retarded and Developmentally Disabled Children

Day care (Title IV-A) funds are used in the State of North Dakota to provide residential camping for 600 mentally retarded and developmentally disabled persons of all ages. Funds are available through regional HEW offices on a 70:30 matching basis.

Construction of a National Children's Center

In the fiscal years 1971 and 1972, the Economic Development Administration of the Department of Commerce provided $3 million in funds toward the construction of a new residential and training facility for handicapped children in Washington, D.C. The facility will be used for an intensive and comprehensive training program for 250 mildly to profoundly retarded adults and children and training 100 high school graduates per year in various phases of work with the handicapped and in the field of child care.

> (N.B. The Economic Development Administration (EDA) authorized through the Public Works and Economic Development Act of 1965, as amended by various public laws, aims to assist in the construction of public facilities needed to initiate and encourage long-term economic growth in geographic areas where economic growth is lagging behind the rest of the Nation. This project described above is particularly unique in that it is the only known instance in which human services to the handicapped was proposed from the viewpoint of economic impact on an area.)

OUTLOOK

The very long lead times needed to arrange contract and grant awards demand that soliciting organizations anticipate program trends as far in advance as possible. Some trends or signs of trends which might affect organizations serving the developmentally disabled are listed below:

The *Revenue Sharing bill,* recently signed into law, will provide states with "no strings attached" monies. The extent to which revenue sharing will be used to supplement health, educational, or social services funds will be determined at the state and local levels.

HR-1, recently signed into law, does not include AFDC welfare reform provisions but does include extended Medicare benefits to disabled recipients of social security and other assistance provisions that will affect the disabled.

Vocational Rehabilitation Amendments, vetoed after the closing of the session, will probably come up again in the first session of the 93rd Congress.

Social Security Title XIX requirements for screening children and youth for ailments, the implementation of which has been long delayed, is gradually being clarified.

Veterans Administration program of assistance for medical education, signed into law on October 24, 1972, will provide assistance to educational institutions for the training of allied health personnel.

If enacted, *the Allied Services Bill,* in Congressional committees, will encourage coordination and consolidation of human service programs at the state and local levels and will have authority to transfer funds between specified Federal programs including vocational rehabilitation and developmental disabilities.

The *1972 Economic Opportunity Amendments* mandated that 10% of Headstart enrollment opportunities will be made available to handicapped children. Guidelines to implement this new statutory provision are expected to be issued soon by the Office of Child Development.

Transportation provisions are being drafted that we allow payments for transportation of children or for transportation subsidies within certain mileage to schools, for payments of transportation to and from the hospital and other necessary services, for payments to and from rehabilitation centers, and to certain categories of people receiving public assistance.